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The purpose of this research study was to understand the truths and the realities of women living with HIV (WLWH) regarding their intimate relationship power and reproductive decision-making. To meet the objective of this research study, the nurse researcher used the philosophical underpinnings of Husserl's phenomenology to guide this qualitative descriptive phenomenological study. Nine WLWH from two urban cities in North Carolina were interviewed, face-to-face, for the study. The interviews were transcribed and then analyzed using the Listening Guide, a voice-centered relational method.

Data analysis yielded three thematic categories: The three themes revealed are as follows: (a) I have my tribe, (b) I have the power, and (c) I am positive, but I am normal, and I am informed. These WLWH had influential sources of support and were capable of disclosing their HIV status to their significant others, therefore demonstrating personal power. This feeling of power lead to favorable intimate relationship power dynamics between the women and their partners which had a positive impact on sexual and reproductive decision-making. The study findings have implications for nursing practice and provide direction for future needed research.

THE LIVED EXPERIENCE OF WOMEN LIVING WITH HIV REGARDING INTIMATE RELATIONSHIP POWER AND REPRODUCTIVE DECISION-MAKING

by

Shaheerah Nur Id-Din Eruotor

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Susan Letvak
Committee Chair

This dissertation is dedicated to Sabur A. Nur Id-Din, my daddy.

We started this journey together, but unfortunately we were unable to finish together. Although our journeys are now two separate ones, I know you are still what you have always been and that is a constant source of encouragement and endless love in my life. I will love you forever.

APPROVAL PAGE

This dissertation, written by Shaheerah Nur Id-Din Eruotor, has been approved by the following committee of the Faculty of The Graduate School at The University of North Carolina at Greensboro.

Committee Chair Susan Letvak

Committee Members Yolanda M. VanRiel

Lynne P. Lewallen

Debra C. Wallace

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Date of Final Oral Examination

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CHAPTER I

INTRODUCTION

Background of the Problem

Due to innovative medical advances in healthcare, the human immunodeficiency virus (HIV) is no longer considered an automatic death sentence as it once was in the 1980s and 1990s. Although great public health efforts have been made to reduce the number of new HIV infections in the United States, there is still a significant number of people living with HIV. Specifically, the Southern region of the United States is experiencing the "greatest burden" of increasing HIV rates and adverse health-related outcomes, including death. North Carolina's HIV mortality rates are 19.1-21.3 per 1,000 people, which is the second to the largest quartile for the country. According to the Centers for Disease Control and Prevention (CDC, 2016), as a result of these mortality rates, the Southern region of the United States is now known as the new "HIV epicenter." North Carolina is ranked number six out of the ten states with the highest number of new HIV diagnoses (CDC, 2019b).

According to the CDC (2019b), approximately 1.1 million people are living with HIV in the United States. Of the 1.1 million people living with HIV, 19% are women (CDC, 2019c). Interestingly, African American women represent 69% of all HIV diagnoses in the South (CDC, 2016). Women living with HIV (WLWH) are of particular concern as there are effects of having the virus that are gender-specific, meaning the virus

has a unique way of impacting the health of women. HIV has specific biological and psychological effects on women. Often the biological effects of HIV are noted in the exacerbation of other health conditions. For WLWH, there are psychological factors that impact how they cope with their illness, utilize support systems, and deal with stigma and HIV status disclosure (Baumgartner, 2007; Carlsson-Lalloo, Rusner, Mellgren, & Berg, 2016; Du Plessis, 2011).

WLWH who are of childbearing age are dealing with matters related to reproductive decision-making, issues with healthcare provider inquiry, considerations of pregnancy desire and intentions, unplanned pregnancies, and/or contraceptives. As WLWH are engaging in reproductive decision-making processes, they may be involved in intimate relationships with varying power dynamics. Additionally, a common occurrence amongst WLWH is the presence of intimate partner violence (CDC, 2014a).

Significance

This study is important as it was conducted in two urban cities in North Carolina, one of the states identified in the "epicenter." This study begins to lay the groundwork for future interventions that will reinforce behavior change, educate, and support WLWH. The CDC has identified these actions as measures that will begin to address HIV health disparities in the new epicenter for HIV, the South (CDC, 2016). Conducting a qualitative study using a descriptive phenomenological methodology helped the nurse researcher to understand, describe and disseminate details about how power dynamics in intimate relationships influence reproductive decision-making and identified other important variables that impact the reproductive decision-making process in WLWH.

Understanding the impact of relationship power on reproductive decision-making in WLWH highlights the need for additional health care interventions; interventions that focus on nursing care, which will empower, motivate, and support WLWH so that they can adequately prepare for or prevent motherhood. In the case of WLWH, part of being adequately prepared for motherhood entails women being on appropriate antiretroviral therapy **(**ART); these therapies help to suppress viral loads, thus decreasing the chances of transmitting the virus to seronegative partners and unborn babies (U.S. Department of Health and Human Services, 2018). Decreasing the transmission rates of HIV to seronegative partners and unborn babies addresses an objective of the National HIV/AIDS Strategy (NHAS), which is to decrease the number of people who will test newly positive for HIV (NHAS, 2015). Furthermore, when WLWH are virally suppressed, their health outcomes are improved. Improving health outcomes in individuals with HIV is another objective of the NHAS (HIV.gov, 2017; National HIV/AIDS Strategy, 2015). According to the CDC, being virally suppressed not only improves the health of the individual with HIV, but it also prevents the transmission of the virus to an HIV-negative person (CDC, 2019a). This statement by the CDC is paramount as it supports the many campaigns that have tried to bring awareness to this breakthrough in HIV care with the slogan "undetectable equals untransmittable," or simply stated, U=U (National Institute of Allergy and Infectious Disease, 2018).

Knowing which WLWH would benefit from being empowered can help these women confidently express and follow through with their reproductive desires and intentions; the aim would be to help these women advocate for barrier protection and

additional contraceptive methods if desired. Lastly, the evidence from this study provided insight into community resources, social services, and nursing care that are needed for this unique population. Additional resources and individualized nursing care are steps forward in decreasing the number of health disparities related to HIV. Decreasing the number of health-related HIV disparities is another objective of the NHAS.

Theoretical Framework

Phenomenology

The philosophical underpinnings of phenomenology provided the scientific framework in which a research question, method, analysis, and findings were explored. The era of phenomenology dates back to the early 1900s, which consisted of the preparatory, German, and French phases. The term phenomenology is the combination of the two Greek words "phainomenon" and "logos." Phainnomenon means phenomena, or "the various ways in which things appear," and logos means to give account, thus giving account to phenomena (Sokolowski, 2000, p. 13). In sum, Sokolowski (2000) has defined phenomenology as "the study of human experience and of the ways things present themselves to us in and through such experience" (p. 2).

Intentionality

According to Streubert and Carpenter (2011), Franz Brentano, a German philosopher, is credited with highlighting the "scientific rigor" of phenomenology. Brentano concerned himself with providing a clear understanding of the concept of intentionality (Brentano, 1874/2014), which is the foundation of phenomenology (Sokolowski, 2000). Intentionality, when defined philosophically, is the mental capacity

to be “conscious” or “aware” (McIntyre & Smith, 1989), or in other terms, “the conscious relationship we have to an object” (Sokolowski, 2000, p. 8). According to the works of Brentano (1874/2014), “every mental phenomenon is characterized by . . . the intentional inexistence of an object” (p. 68). The essence of Brentano’s intentionality is there are no mental acts that are not aimed toward an object, nor is there a “desire without an object that is desired” (p. 68). McIntyre and Smith (1989) go further to explain Brentano’s intentionality to mean that the mind and experiences are always “directed toward something”; therefore, “all mental phenomena are intentional” and “only mental phenomena are intentional” (p. 2).

Husserlian Phenomenology

Edmund Husserl is one of the leading phenomenological philosophers of the German era. Husserl was a proponent of the idea that the sciences should be grounded in the intricate concerns of human beings (Husserl, 1984/2008; Streubert & Carpenter, 2011), and according to Zahavi (2003), the philosophical movement of phenomenology should bring to the forefront a clear way of understanding “the questions concerning the being and the nature of reality” (Zahavi, 2003, p. 44). For Husserl, intentionality was a core tenet of phenomenology, just as it was for Brentano. However, Husserl disagreed with Brentano’s belief that *all* mental phenomena are intentional. Husserl instead believed that “only states of conscious awareness are intentional” (McIntyre & Smith, 1989, p. 2); however, phenomenology should be flexible enough to consider the unconscious thoughts that may be contributory to the understanding of relationships and objects (McIntyre & Smith, 1989). To further expand upon intentionality and how

phenomena are understood, Husserl asserted that experiences are as important as conscious and unconscious thoughts. In sum, Husserl believed that conscious and some unconscious thoughts *and* experiences are valid and should be considered as realities, thus providing evidence for understanding phenomena (Husserl, 1931/2014; McIntyre & Smith, 1989). In other words, it is not just the mental or the physical experiences that provide meaning or insight into circumstances, but the intricate workings of the two together (Christensen, Welch, & Barr, 2017; Olafson, 1975).

Husserl respected the scientific rigor used in other disciplines. However, he believed that the notion of theories and "presuppositions" used to guide inquiry into phenomena, had no place in phenomenology. In order for phenomenological scientific inquiry to occur, one has to be guided by "what is actively given" versus by "theoretical commitment." Thus, scientific evidence is provided through the experience. According to Husserl, in order for experience to lend itself to what is, therefore, true of the phenomena, one must be willing to "epoché," or bracket/reduce (Zahavi, 2003).

Because Husserl supports the notion that one's mental processes and experiences are the only ways to understanding truths, he claimed that in order to obtain these truths, those investigating the phenomena should implement an act of bracketing. The act of bracketing is a consciousness that occurs from exploring personal beliefs and ideas regarding a phenomenon and then setting those beliefs to the side in attempts to not impose on the truths being investigated (Richards & Morse, 2013). When bracketing is imposed, the researcher is then said to be able to observe and describe the phenomenon in a way that provides the most authentic essence (Olafson, 1975), therefore being

descriptive phenomenology. Descriptive phenomenology has been defined as the "direct exploration, analysis and description of particular phenomena, as free as possible from unexamined presuppositions, aiming at maximum intuitive presentation" (Spiegelberg, 1975, p. 57)

Husserl (1931/2014) frequently mentioned how the rigor of descriptive phenomenology is to entail descriptions of the essence of the phenomena in query. The essence, or as Husserl stated, "that which appears as such," is to be described "faithfully" (Husserl, 1931/2014, pp. 259). Husserl understood that his views of what descriptive phenomenology is were unprecedented, yet validated in its scientific rigor, and with great profoundness he stated

> Our procedure is that of a scientific traveller in an unknown part of the world who carefully describes what he finds on the trackless ways he takes-ways that will not always be the shortest… In a similar temper we wish in what further lies before us to be loyal expounders of phenomenological formations, and for the rest to preserve the habit of inner freedom even in regard to our own descriptions (Husserl, 1931/2014, pp. 279–280).

The Application of Husserl's Phenomenology

In keeping with the philosophical underpinnings of Husserl's phenomenology to guide the research inquiry, WLWH were interviewed one-on-one and in person. The objective was to describe the level of consciousness or intentionality that surrounds their perception of intimate relationship power and the impact on reproductive decision-making. Intimate relationship power for the purpose of this study was the perceived degree of influence (Hall & Knox, 2019) WLWH have in their intimate relationships. However, it is during the analysis process that unconscious thoughts may be revealed

which are relevant but similarly intentional. These mental processes, both conscious and unconscious, along with the life experiences of WLWH, minus the presuppositions of the nurse researcher, provided the evidence to understand the phenomenon: “What is the lived experience of women living with HIV regarding intimate relationship power and reproductive decision-making?”

Purpose

The purpose of this research study was to understand the truths and the realities of women living with HIV (WLWH) regarding their intimate relationship power and reproductive decision-making.

Research Question

Gaps were identified from a review of the literature; as a result, this research study addressed the following question: “What is the lived experience of WLWH regarding intimate relationship power and reproductive decision-making?” This research study aimed to understand how WLWH described the power dynamics within their relationship and if or how these dynamics shaped their reproductive decision-making. The research question was addressed using a phenomenological framework and a qualitative descriptive phenomenological methodology.

Definitions

For the purpose of this research study the following terms were defined:

1. WLWH: Women living with Human Immunodeficiency Virus.
2. Intimate relationship power: The perceived degree of influence WLWH have in their intimate relationships.

3. Reproductive decision-making: Reproductive plans which may include: safe-sex practices, pregnancy prevention or planning, preconception counseling, or prenatal care.
4. Desire to have children: Wishing or longing for children (Chen, Phillips, Kanouse, Collins, & Miu, 2001; Finocchario-Kessler, Sweat, et al., 2010).
5. Intentions to have children: The measures taken to conceive with the expectation of childbearing (Finocchario-Kessler, Sweat, et al., 2010).

Assumptions

The assumptions for this research study were:

1. There are varying relationship dynamics among WLWH and their sexual partners; though these dynamics vary, commonalities are identifiable.
2. WLWH have experiences that are unique and complex, all which impact reproductive decision-making.
3. There are multiple ways of knowing and a qualitative descriptive phenomenological study is an avenue to explore new truths regarding WLWH based on their realities.

Delimitations

The limits of this research study were to individuals who are biologically female and

1. Living with HIV
2. 18–44 years of age

3. In heterosexual relationships
4. English speaking

Summary

Chapter I provided a summary of the research study that aimed to understand the lived experience of WLWH, their intimate relationship power and reproductive decision-making processes. The background pertaining to HIV and how the diagnosis has gender-specific manifestations were outlined and are discussed more in-depth in Chapter II. This research study is significant as it attempted to address national efforts to improve health outcomes associated with living with HIV. Husserlian's phenomenology was used to guide and serve as a framework to explore the research question: "What is the lived experience of WLWH regarding intimate relationship power and reproductive decision-making?"

CHAPTER II

LITERATURE REVIEW

The purpose of this chapter is to report the state of the science as it relates to women living with human immunodeficiency virus (WLWH; HIV). This chapter discusses how biological and psychological factors contribute to the health of women. A brief discussion about HIV and the impact that the virus has on women's health is presented. This chapter synthesizes the current knowledge base, the importance of reproductive decision-making, and intimate relationship power among WLWH. The gaps in the literature regarding WLWH are identified in addition to ideas for how the research study addresses these gaps.

The Significance of Women

There are distinct differences between the female and male sex, along with noteworthy gender differences; this dichotomy has been shown to have significant health outcomes and implications, especially for women (Smith, 2006; World Health Organization, 2017b). Understanding that sex and gender are not synonymous is imperative when addressing health care issues. Sex denotes the chromosomal traits that distinguish individuals biologically as male or female. Gender refers to the social and cultural norms that shape psychological and behavioral expectations for men and women (American Psychological Association, 2015; World Health Organization, 2015). These biological and sociocultural factors influence the health and lives of women, making

women's health an important area of study in healthcare. The biological factors pertaining to women, such as hormones, genetics, and anatomy, have been identified as health outcome predictors in many disease processes, including HIV (Addo & Altfeld, 2014). The sociocultural factors that have contributed to the lived experiences of women and have impacted their health are the norms that influence access to health care, education and economic empowerment (Vlassoff, 2007; World Health Organization, 2017b). These distinct biological and sociocultural differences have led to specialized areas of health care and research that primarily focus on women's health, and even more so, on women living with HIV.

Pathophysiology of Human Immunodeficiency Virus

HIV continues to be a public health issue. The impact of HIV is of great concern because of the effects it has on the immune system. The human immune system provides a natural defense against viral and disease processes that could potentially harm an individual. HIV causes a weakening of the immune system, inhibiting the body's ability to fight off infections. When an individual is exposed to HIV and the virus makes contact with dendritic cells, there is an immunological cascade that follows. The infected dendritic cells bind to other complex proteins in the body, storing the virus. The storage of the virus then causes a sequela of reactions, which results in the virus binding to cluster of differentiation 4 (CD4) proteins found on white blood cells (WBCs); the primary role of WBCs is to fight infections. Once the virus binds to the proteins found on WBCs, the WBCs undergo destruction. If HIV destroys a significant number of WBCs, the infected person enters into a state of acquired immunodeficiency syndrome (AIDS;

[CDC, 2019a; Fauci, 2007]). Once AIDS is present, the immune system is no longer able to fight off infections, and the individual may die as a result of opportunistic infections.

HIV and Women

Approximately 1.1 million Americans were reported to be living with HIV in 2016 (CDC, 2019d), and in 2017, 19% of those living with the virus were women (CDC, 2019c). Interestingly, the majority of the WLWH in the United States are in their reproductive years of life (The Henry J. Kaiser Family Foundation, 2014). HIV disproportionately impacts African American women at alarming rates; they account for the majority of female HIV infections (CDC, 2017b). According to the CDC (2019c), a majority of the WLWH acquire the virus through heterosexual intercourse. When compared to men, the evidence shows that the anatomy of women puts them at an increased risk of acquiring HIV. The vagina's "large surface area" and fragile lining, which may tear during sexual intercourse, can leave women vulnerable when exposed to the virus (National Institutes of Health, 2016).

Women Living with HIV

Twenty-five years ago, the prognosis for WLWH was poor, and life expectancy was short. However, HIV is now considered a chronic condition, meaning that if managed appropriately, women can live healthier and longer lives. The improved prognosis associated with HIV is the result of medical advancements. Therapies known as highly active antiretroviral therapy (HAART) are helping WLWH have an improved quality of life and lifespans similar to those who are HIV-negative (Health Resources and Services Administration, 2016; HIV Medicine Association, 2017). Although there are

medication regimens available that significantly improve the lives of WLWH, there remain biological and psychological effects that manifest as a result of having the virus.

Biological Effects

Although medication regimens have improved overall health outcomes for WLWH, there are still health effects and specific considerations that must be understood, making WLWH a unique population. HIV uniquely affects women in ways that are different from men. In women, HIV can cause, an increase in vaginal yeast infections and pelvic inflammatory diseases, cervical cancers, early onset of menopause, exacerbation of gastrointestinal and endocrine issues, pregnancy complications, and transmission of the virus to unborn babies through vertical transmission (National Institutes of Health, 2016; U.S. Department of Health and Human Services, 2017).

Psychological Effects

As discussed in the previous section, HIV has unique biological effects on women. These gender-specific variations are not only limited to biological responses; there are psychological gender differences that can be seen in WLWH. Therefore, when attempting to comprehend the scope of life of WLWH it is imperative to understand that there is an intersection of biological and psychological factors that shape the experiences of these women (Bowleg, Belgrave, & Reisen, 2000; Caiola, Barroso, & Docherty, 2017; Goel & Bale, 2009) and how they may cope with living with HIV.

The psychological factors that can shape the experiences of WLWH influence how the women cope with their diagnosis. The initial psychological reaction to a diagnosis of HIV varies naturally from woman to woman. Reactions can vary from

feelings of anger, sadness, hopelessness to lost identities (Bezuidenhoudt et al., n.d.; Ingram & Hutchinson, 1999). A major contributing factor to how women will react to the news of having HIV is due to the context in which HIV has been culturally defined (Sayles, Ryan, Silver, Sarkisian, & Cunningham, 2007). Factors that impact the identity of WLWH begin internally and involve mentally processing the new diagnosis and the significance of the diagnosis as it pertains to their lives going forward (Baumgartner, 2007; Du Plessis, 2011; Sayles et al., 2007).

Coping

According to Sayles et al. (2007), HIV-related stigma framework, two psychological processes can occur and dramatically shape the identities of individuals at the time of being diagnosed with HIV. Individuals living with HIV can either go into denial and/or isolation, or they can use their diagnosis to empower them and be a catalyst for change and "self-acceptance." Although Sayles et al. (2007) introduced an innovative framework to conceptualize the mental processes that can occur in general, other authors have specifically highlighted the reality of denial and isolation that WLWH often experience as they are trying to redefine their identities after being diagnosed with HIV (Baumgartner, 2007; Bezuidenhoudt et al., n.d.; Du Plessis, 2011; Leenerts & Magilvy, 2000). When WLWH use denial as a coping mechanism, they are less likely to see positive changes in overall physical and mental health quality of life (Kamen et al., 2012; Weaver et al., 2004). When women use either denial or isolation to cope with their HIV diagnosis, they may find themselves in a cycle of conflict with their social support

system. This conflict among social support systems continues to perpetuate stress in the lives of these women (Fleishman et al., 2000).

Support groups are relevant in that they can impact the lives of women, influencing how well they cope with stress. Taylor et al. (2000) explain how women "tend-and-befriend' to deal with life stressors. Tend-and-befriend is a theory that explains how women who are prone to stressful situations seek support and protection from social groups. For WLWH, it is not uncommon for them to experience a significant amount of stress as a result of their diagnosis. In response to having HIV, these women may tend-and-befriend or display actions of positive growth, which involves seeking emotional support (Taylor et al., 2000; Vosvick, Martin, Smith, & Jenkins, 2010). When WLWH use constructive coping strategies such as tend-and-befriend or actions of positive growth and avoid maladaptive coping strategies, they are more likely to deter depressive symptoms (Vosvick et al., 2010).

Mental Health

Depression and other mental health conditions are common in people living with HIV; however, a review of the literature has shown that WLWH experience mental health conditions and psychological stressors at higher rates when compared to men living with HIV (Bhatia, & Munjal, 2014; Marlink, Kao, & Hsieh, 2001). Interestingly, the overall health outcomes of WLWH who experience specific depressive symptoms are impacted as these women have increased neurological complaints, weight loss (Vosvick et al., 2010), and poor medication adherence thus depicting the intersection of biological and psychological effects of HIV (Wagner et al., 2011). The weight of depression or

emotional distress that is commonly seen in WLWH is often attributed to their assigned roles and obligations (Vosvick et al., 2010) as women. Due to cultural norms in the United States, women have been assigned gender-related roles and obligations, such as being the primary caregivers for children and family members (Caiola et al., 2017; Connell, 1987). For WLWH, the "complexity" of the impact of having HIV coupled with societal norms and expectations can be emotionally and mentally strenuous on the lives and health of these women (Marlink et al., 2001).

Balancing Relationships

According to Hackl, Somlai, Kelly, and Kalichman (1997), many WLWH have historically experienced "relationship disruption" (p. 54). The authors suggest that WLWH often do not have the desired support needed to cope with having HIV because they are not willing to disclose their HIV-seropositive status due to a fear of stigma. However, when WLWH disclose their HIV status to their families, the women may often be expected to continue to fulfill their traditional roles and obligations, which some WLWH find challenging. While balancing roles such as being a mother can be challenging for some WLWH, other WLWH find traditional roles such as motherhood to be a protective mechanism, deterring negative maladaptive behaviors (Caiola et al., 2017). Using motherhood to accept and cope with having HIV can empower women (Caiola et al., 2017; Sayles et al., 2007), and even increase their chances of living a longer life despite having HIV (Lee & Rotheram-Borus, 2001).

Stigma and Disclosing

When discussing the psychological processes that WLWH undergo, it is imperative to discuss HIV disclosure and the stigma that can result from such disclosure. As WLWH are cognitively processing the extent of what having HIV means to them, they are contemplating interpersonal reactions, such as stigma, that may be endured as a result of disclosing their condition (Baumgartner, 2007; Carlsson-Lalloo et al., 2016; Leenerts & Magilvy, 2000). Stigma occurs when an individual is "assigned a master status trait that will discredit all other traits and change their social identity" (Goffman, 1963, p. 10; Hasan et al., 2012, p. 22). Stigma can further be categorized as either felt stigma, which is the fear of being labeled or discriminated against, or as enacted stigma, which is the actual experience of being labeled and discriminated against (Florom-Smith & De Santis, 2012; Scambler, 1998). In tandem with felt and enacted stigma, WLWH can experience courtesy stigma. Courtesy stigma is felt or enacted stigma that results when stigma is extended from the "stigmatized" to family and/or friends (Goffman, 1963).

For many WLWH, disclosing their status is a true challenge; felt stigma for them is real and often the motivation for delaying disclosure (Barroso et al., 2014; Clum et al., 2013; Dass-Brailsford, Eckman, & Kwasnik, 2014). Often this delaying disclosure of one's HIV status is from potential sexual partners (Clum et al., 2013). WLWH are not only experiencing felt stigma but enacted stigma, especially from health care providers (Baumgartner, 2007; Cuca & Rose, 2015; Finocchario-Kessler, Dariotis, et al., 2010; Finocchario-Kessler et al., 2012; Sayles et al., 2007; Vyavaharkar et al., 2011). WLWH have often noted health care providers as a source of stigma, and therefore would not

disclose their HIV status to these providers (Leyva-Moral et al., 2018; Sayles et al., 2007). This type of nondisclosure to healthcare professionals can have adverse effects on the health of these women as health care decisions vary depending on immune health (Sayles et al., 2007).

WLWH who may have not disclosed their HIV status to anyone may still experience stigma known as courtesy stigma. For example, if the children or significant others of these women are known to have HIV, the women themselves may experience felt courtesy stigma by feeling that others view them as contagious. Also, WLWH may experience enacted courtesy stigma by being threatened and isolated (Ingram & Hutchinson, 1999).

When WLWH are not comfortable enough to disclose their status, it can have profound effects on their mental and physical health (Carter, Kraft, et al., 2013; Sayles et al., 2007; Vyavaharkar et al., 2011). As mentioned earlier, WLWH who have not yet disclosed their HIV status to anyone or are experiencing enacted courtesy stigma, often live in social isolation. Social isolation has been linked to increased depressive symptoms in individuals living with HIV (Hasan et al., 2012). For WLWH who experience stigma due to their HIV status, such stigma could compromise the health of their partners and also jeopardize their health care by missing opportunities to engage with health care providers (Carter, Bourgeois, et al., 2013; Sayles et al., 2007; Vyavaharkar et al., 2011)

Reproductive Decision-making

Reproductive decision-making entails individuals making decisions that impact their reproductive health. Reproductive health is a state of “complete physical, mental

and social well-being, and not merely the absence of reproductive disease or infirmity" (World Health Organization, 2011, p. 6). For women, achieving optimal reproductive health depends on having access to reproductive health care that provides services for screening and treatments for cervical cancer, breast cancer, and sexually transmitted infections along with services for contraceptive care and pregnancy management. Access to reproductive health care should include services for women who are victims of intimate partner violence (IPV; World Health Organization, 2018). This section focuses primarily on reproductive decision-making to the extent to which pregnancy outcomes and contraceptive methods are considered; therefore, the term "reproductive decision-making" will be used to denote these concepts.

Healthcare Provider Inquiry

The reproductive decision-making process should involve health care providers inquiring of women about their desires and intentions to have children in the future and about their contraceptive needs (World Health Organization, 2014). Understanding women's desires and intentions regarding childbearing and contraceptive methods will allow health care providers to educate and collaborate with women in devising reproductive plans that will best suit their needs (CDC, 2014b). Not all WLWH are having discussions regarding reproductive decision-making with their health care provider. It has been shown that approximately 25% - 55% of WLWH do not recall having reproductive decision-making conversations with their health care providers (Badell et al., 2012; Finocchario-Kessler, Dariotis, et al., 2010; Finocchario-Kessler et al., 2012; Mindry et al., 2012; Rahangdale et al., 2014; Squires et al., 2011). Although

these women do not recall having specific conversations about their reproductive agenda with their healthcare provider, they do know that these types of conversations are important (Finocchario-Kessler et al., 2012; Mindry et al., 2015; Squires et al., 2011). These conversations are so important that WLWH often resort to seeking family planning advice from laypersons (Amutah, Gifuni, & Wesley, 2016). It is imperative that healthcare providers not have a one-time discussion with WLWH regarding their reproductive agenda, but rather have frequent discussions where they inquire about these women's reproductive plans. It is important to frequently inquire about the reproductive agenda of these women as reproductive plans can vary throughout the women's lives.

Pregnancy Desires and Intentions

Although conversations are not always occurring between health care providers and WLWH, it does not negate the fact that these women have reproductive agendas. Some WLWH desire and intend to have children in the future (Fair et al., 2012; Finocchario-Kessler et al., 2012; Finocchario-Kessler, Sweat, et al., 2010; D. Mindry et al., 2012; Rhodes, Cu-Uvin, & Rana, 2016; Sutton, Frazier, Short, & Skarbinski, 2014). Desiring to have children is the "wishing" or "longing" for children; intending to have children are the measures taken to conceive with the expectation of childbearing (Finocchario-Kessler, Sweat, et al., 2010). In an extensive review of the literature by Carter, Kraft, et al. (2013), it was found that approximately 80% of WLWH had childbearing desires. Many WLWH want to have children in the future, and others intend to have children (Finocchario-Kessler et al., 2012; Finocchario-Kessler, Sweat, et al.,

2010). When WLWH are trying to conceive, they may stop using condoms and start adhering to a stricter antiviral regimen (Finocchario-Kessler et al., 2012)

Addressing reproductive decision-making for all women not only has political and social implications (Price & Hawkins, 2007; Verbiest, Malin, Drummonds, & Kotelchuck, 2016), but most importantly, it has health implications—health implications that are especially true for WLWH and their sexual partners. This lack of conversation regarding reproductive decision-making with WLWH can place seronegative partners of WLWH at risk of contracting HIV. Many WLWH have seronegative partners (Carter, Kraft, et al., 2013; Fair et al., 2012; Rhodes et al., 2016), and many WLWH desiring pregnancy have seronegative partners (Finocchario-Kessler et al., 2012; Finocchario-Kessler, Sweat, et al., 2010; Rhodes et al., 2016). Identifying WLWH who desire and intend to have children provides the opportunity to educate them how to safely conceive and to not horizontally and vertically transmit the virus to sexual partners and unborn babies. These discussions not only fulfill the reproductive agenda of WLWH but reduce the number of new HIV infections (Finocchario-Kessler et al., 2012; HIV Medicine Association, 2017; Rahangdale et al., 2014). According to the CDC, when the viral loads of people living with HIV are undetectable, the is “no risk of sexually transmitting the virus to an HIV-negative partner” (CDC, 2019a, p.1).

Unplanned Pregnancies

A majority of WLWH in the United States are in their reproductive years of life. It is imperative to understand the importance of addressing the reproductive decision-making needs of these women and the impact on pregnancy rates and outcomes. The

pregnancy desires and rates among WLWH mirror those of HIV-negative women (Badell et al., 2012; Cuca & Rose, 2015; Haddad et al., 2017; Mindry et al., 2012). In the most recent data available from the CDC (2017), it is approximated that 8,500 WLWH give birth each year. In many situations, much like HIV-negative women, these pregnancies for various reasons are unplanned (Cuca & Rose, 2015; Finer & Zolna, 2011; Finocchario-Kessler, Sweat, et al., 2010; Haddad et al., 2017; Sutton, Frazier, et al., 2014; Sutton, Patel, & Frazier, 2014). An unplanned pregnancy is an unintended pregnancy. Unintended pregnancies are either classified as "mistimed" or "unwanted" (Guttmacher Institute, 2016). In a study by Koenig, Espinoza, Hodge, and Ruffo (2007), 1,183 babies were born to 1,090 WLWH, and 83% of these births were unplanned. In a more recent study by Sutton, Patel, et al. (2014), out of 620 pregnancies of WLWH, approximately 70% were unplanned.

Unplanned pregnancies among WLWH have health implications. The first health implication is the risk of transmitting the virus to the unborn child, referred to as mother-to-child transmission (MTCT). To prevent MTCT, it is recommended that WLWH take a regimen of medication during pregnancy, labor, and delivery (CDC, 2017c; Read et al., 2012). Often when pregnancy is unplanned in WLWH, the effect of these medications is delayed and results in an increase in the MTCT rates (Read et al., 2012). In 2014, the CDC reported that there were 1,995 children in the United States living with HIV as a result of MTCT (CDC, 2017c). The second health implication that unplanned pregnancies has on WLWH is the overall effect of pregnancy on the women's health. If pregnancies are not planned when WLWH are at their healthiest, there is an increased

risk of several poor health outcomes, including opportunistic infections and mortality (McIntyre, 2003). The third implication that unplanned pregnancies can have on WLWH is the mental health consequences from having to decide whether to terminate the pregnancy. For women in general, making such decisions has been linked to increased depression and anxiety symptoms (Biggs, Upadhyay, & McCulloch, 2017; Craft, Delaney, Bautista, & Serovich, 2007). For WLWH, having depression as comorbidity is not uncommon (Bhatia, & Munjal, 2014; Marlink et al., 2001). Depression, coupled with having to make such life-changing decisions, could further compromise the mental health well-being of the WLWH.

Contraceptives

In general, contraceptives are methods taken to decrease women's chances of becoming pregnant. The only method that is 100% effective in preventing pregnancy is abstinence. In the United States, common contraceptives are birth control pills, injections, transdermal patches, spermicides, subdermal implants, vaginal implants, intrauterine devices (IUDs), condoms, and sterilization techniques (CDC, 2017a). All contraceptive methods mentioned except for condoms have to be prescribed by a licensed health care provider. All available contraceptives in the United States can be prescribed safely to WLWH (CDC, 2012). Although various contraceptives are safe to use by WLWH, many health care providers are uncertain about drug-to-drug interactions and therefore are reluctant to prescribe certain methods (Badell et al., 2012; Sharma & Walmsley, 2015). WLWH reproductive decision-making conversations with their health care provider must

be evaluated on an individualized basis in order to determine the most suitable and safest contraceptive options for them.

There is a lack of health care provider communication with WLWH regarding their reproductive agenda (Badell et al., 2012; Finocchario-Kessler, Dariotis, et al., 2010). This lack of conversation around reproductive decision-making can lead to unplanned pregnancies, which could be attributable to the types of contraceptive methods being used by WLWH. There has been significant evidence that shows WLWH are experiencing "contraceptive failure" and are therefore getting pregnant (Lindsay et al., 1995; Massad et al., 2004). According to the World Health Organization (2015), individuals living with HIV should be using dual methods to prevent unplanned pregnancies, which will reduce the chances of transmitting HIV and acquiring sexually transmitted infections. Dual methods can include the use of condoms and either hormonal contraceptives, IUDs, or sterilization.

Interestingly, although the World Health Organization recommends the use of dual methods in those living with HIV, the incidence of unplanned pregnancy is still an issue for WLWH who are using dual methods (Delaney & Haddad, 2016). One identified reason for unplanned pregnancies in those who use a dual method regardless of HIV status is the fact that most people do not use dual methods (with one method being condoms) consistently throughout each act of sexual intercourse (Higgins et al., 2014). In order to understand contraceptive failure among WLWH, it may be necessary to investigate further the current types of contraceptives being recommended to this population.

As previously mentioned, WLWH are good candidates for various types of contraceptives. However, the literature shows that some methods are being utilized more than others by WLWH. In general, the majority of women in the United States are using birth control pills as their primary method of contraception (Daniels, Daugherty, & Jones, 2014). However, WLWH are using condoms as their primary method of contraception (Carter, Kraft et al., 2013; Cocohoba, 2010; Delaney & Haddad, 2016; Massad et al., 2007; Raiford, Wingood, & DiClemente, 2007). The concern with condoms being the primary method of contraception for WLWH is their effectiveness in preventing pregnancy. When condoms are used as directed, they are 98% effective as a contraceptive method (World Health Organization, 2017a). The majority of individuals who rely on condoms as their primary method of contraception use them inconsistently or incorrectly, resulting in condoms only being approximately 85% effective for contraception (Leonard, Markham, Bui, Shegog, & Paul, 2010; World Health Organization, 2017a).

It appears that WLWH are relying on condoms as their primary method of contraception because it is being recommended/presented to them by their health care providers (Coll et al., 2015). However, for many WLWH, this contraceptive option is unsatisfactory (Rahangdale et al., 2014). Contraceptive methods must be discussed and agreed upon by both WLWH and their health care providers. When WLWH are not fully involved in the decision-making process regarding their reproductive agenda, many report feelings of partial or complete dissatisfaction with their current method of contraception. The majority of these women report that they are not fully aware of the various methods of contraceptives. When reproductive decision-making is not discussed

thoroughly or does not consider a woman's best interest, WLWH can experience feelings of regret after utilizing the recommended method of contraception. The feeling of regret is especially true when WLWH are only presented with permanent sterilization as a form of contraception because of their HIV status. These women often regret their reproductive decisions as their reproductive desires have changed (Badell et al., 2012).

The information presented validates the importance of reproductive decision-making and the implications of the decision-making process with WLWH. Neglecting to address reproductive decision-making can have serious health care implications. These implications include the possibility of horizontally and vertically transmitting the virus to sexual partners and unborn babies. Also, there is the implication of having an increase in unplanned pregnancies, which could be attributed to contraceptive failure. Lastly, not addressing reproductive decision-making can leave WLWH unsatisfied with their primary method of contraception.

Intimate Relationship Power

Power as a concept, depending on the context in which it is used, can have many meanings in various circumstances. In this section, power will be discussed and defined in the context of intimate heterosexual relationships, thus, intimate relationship power. According to Pulerwitz, Gortmaker, and Dejong (2000), power is the display of power equalities and/or disparities within relationships. Further expanding on power is the notion that in intimate relationships, power is variable and can be displayed as "process" or "outcome" power. Process power is the capability to change or control the other partner's thinking. Outcome power refers to who makes the final decision, which often

impacts the other partner's actions (Farrell, Simpson, & Rothman, 2015). In intimate relationships, power can be the perception (Hall & Knox, 2019) to be able to influence or change one's partner's actions thinking or actions. Many authors have suggested that power and its dynamics manifest in almost all intimate relationships (Lennon, Stewart, & Ledermann, 2013). When there are power differentials in intimate relationships, power often favors the most influential partner (Carli, 1999; Farrell et al., 2015).

In the United States, women have traditionally possessed less power in their relationships due to the segregation of the workforce and jobs described as "women's work." This sexual division of labor causes economic imbalances within the relationships, often causing women to be dependent on men's income, making men more powerful (Connell, 1987; Eagly, 1987). Relationship power dynamics can also contribute to health outcomes (Carli, 1999; Wingood & DiClemente, 2000), and more specifically, relationship power dynamics can influence decision-making centered around reproductive health (Robinson et al., 2017).

Intimate relationship power inequalities are of importance due to the impact they have on intimate partner violence (IPV). Previous research studies have examined power inequalities and the abuse of power in relationships. Power differentials that lead to the abuse of power can be an opportunity for IPV to occur in women (Gaman, Mcafee, Homel, & Jacob, 2017; Gesink, Whiskeyjack, Suntjens, Mihic, & McGilvery, 2016; Krishnan et al., 2008; Rogers, Bidwell, & Wilson, 2005). These findings are of particular importance as they relate to WLWH. For many WLWH, IPV is a salient theme (CDC, 2014a; Clum et al., 2012, 2013; Jennings et al., 2009; Orza et al., 2015; Sowell, Phillips,

Seals, Murdaugh, & Rush, 2002). WLWH are victims of IPV at four times the rate of women who are HIV-negative (CDC, 2014a). Interestingly, the intersection of intimate relationship power inequalities and IPV often leads to poor reproductive health outcomes such as unplanned pregnancies, sexually transmitted infections, and other factors that influence overall reproductive health (Moore, Frohwirth, & Miller, 2010). Based on the information provided, understanding intimate relationship power in WLWH is essential.

Intimate Relationship Power and Reproductive Decision-making

As mentioned in the previous section, the dynamics of intimate relationship power in WLWH are important as they influence reproductive decision-making within relationships. When WLWH exhibit power in their intimate relationships, they have increased self-efficacy in advocating for condom use (Buchmann, 1997; Raiford et al., 2007) and these women are 7.8 more times likely to report consistent condom use than women who were less powerful within their intimate relationships. These women are so powerful in their own right that they will threaten to leave and not engage in sexual intercourse if their partner does not use a barrier method (Clum et al., 2013). Also, WLWH whose sexual partners showed less opposition to condom use were five times more likely to report consistent condom use. WLWH were more likely to use condoms if they thought their partners would not become angry (Raiford et al., 2007).

Intimate Partner Violence and Reproductive Health

Intimate partner violence (IPV) is common among WLWH. The violence can consist of physical, psychological, and/or financial abuse. In 2015, a global study conducted on WLWH and their experiences with violence revealed that of 832 WLWH,

43% experienced IPV before being diagnosed with HIV, and for many of the women, the violence accelerated after their diagnoses. Being a victim of IPV adversely impacts the reproductive health of WLWH (Orza et al., 2015). Often WLWH are forced into sexual situations (Jennings et al., 2009) that result in them having several sexually transmitted infections in addition to HIV (Orza et al., 2015). IPV can result in WLWH having significantly more sexual partners; the sexual partners of these women may also have multiple sexual partners. In these particular circumstances, WLWH are less likely to inquire about their sexual partners' HIV status and less likely to use condoms during sexual intercourse (Clum et al., 2012).

Gaps and Opportunities

A review of the literature has revealed several critical gaps. There have been many studies examining power differentials in WLWH in the United States; however, these studies have been mainly limited to major metropolitan areas, neglecting the Southern part of the country, despite women in the South being impacted at disproportionate rates (Breskin, Adimora, & Westreich, 2017; CDC, 2016; Sowell et al., 2002). This study began to fill the geographical gaps by addressing the growing need for more HIV data on women living in the South. The South has many social determinants of health, such as income inequalities and poverty that are unlike other regions in the United States. These social determinants of health have led to poorer health outcomes. Poorer health outcomes in the South can be attributed to the increase in the prevalence of obesity, diabetes, and cancers. Culturally, the South is not as transparent in discussing matters concerning sexuality; this lack of transparency has led to an increase in HIV

stigma. HIV stigma has been associated with being a barrier to accessing HIV-related health care services (CDC, 2016). North Carolina, a part of the Southern region of the country, is of particular interest as the state has yet to expand its Medicaid coverage. The expansion of Medicaid would allow those with United States residency and incomes below the federal poverty level to automatically qualify for health care coverage (The Henry J. Kaiser Family Foundation, 2016); for many WLWH, this would result in improved health care access. Findings from this study and future studies could provide insight into the health care needs for WLWH, which could be used as evidence needed to prompt policy changes and improve community resources in states like North Carolina.

The second gap identified in the literature involves how many quantitative and interventional studies are being conducted to improve self-efficacy, reduce risky sexual behaviors, and improve overall sexual health outcomes in WLWH. However, the results of those studies are not always as anticipated. The results from these interventions could be more significant and impactful if power dynamics between WLWH and their male partners are addressed in more depth (Robinson et al., 2017). The majority of the studies that consider WLWH and their significant others examine reproductive decision-making influences to the extent of whether or not significant others desire children (Jean, Coll, Monda, Potter, & Jones, 2016; Leyva-Moral et al., 2018). This research study aims to understand the lived experience of WLWH, their perception of the power dynamics in their intimate relationships, and how this impacts their reproductive desires and intentions. Being able to tailor interventions in the future based on results from this study

and similar studies can impact overall sexual health outcomes in WLWH in an unprecedented way.

Summary

Chapter II discussed the biological and psychological gender-specific effects of HIV in women. There are specific factors that influence how well women cope with an HIV diagnosis, which is mainly centered on social support systems and constructs. Addressing reproductive decision-making with WLWH is essential to their reproductive and overall health. Although some WLWH desire and intend to have children in the future, many WLWH are still experiencing unplanned pregnancies. These unplanned pregnancies are the result of absent health care provider communication and contraceptive failure. Intimate relationship power varies in WLWH, and unfortunately, many of these women are finding themselves in situations where IPV is present.

There are gaps in the literature as it pertains to the power dynamics of WLWH in the Southern part of the United States. The current study addressed this gap as it was conducted in urban cities in North Carolina, which is in the South. Another gap identified in the literature is the lack of qualitative studies that aim to understand WLWH and their perception of the power dynamics within their relationships and the impact of these dynamics on reproductive decision-making. This qualitative descriptive phenomenological research study aids in beginning to understand power dynamic perceptions and the significance it has on reproductive decision-making in WLWH and will perhaps strengthen the plethora of quantitative and interventional studies that currently focus on sexual health outcomes.

CHAPTER III

METHODS

Introduction

Qualitative research is a rigorous scientific method that can be used to investigate intimate relationship power and reproductive decision-making in women living with HIV (WLWH). The nurse researcher supports the notion that there are multiple ways of knowing, which is based on the realities of the women participants; one goal of this study was to show value in the women's truths. It was the intention of the nurse researcher to minimize the amount of disruption to the natural environment in which the phenomena were occurring (Streubert & Carpenter, 2011). In general, the way in which qualitative research is conducted depends on how the "social world" is perceived (ontology), the essence of knowledge and how it is "acquired" (epistemology), and the aim and intention of the research (Ritchie, Lewis, Nicholls, & Ormston, 2013).

This chapter discusses the methodology implemented to understand the lived experience of WLWH regarding intimate relationship power and reproductive decision-making. The sampling process, which includes measures taken to protect the rights of human participants, data collection process, and procedure for data analysis, which includes the actions taken to promote trustworthiness, rigor, and replicability, as discussed in the sections below.

Methodology

The purpose of this research study was to describe the phenomenon of the lived experience of WLWH regarding intimate relationship power and reproductive decision-making. To meet the objective of this research study, the nurse researcher used the philosophical underpinnings of Husserl's phenomenology to guide this qualitative descriptive phenomenological study. It was imperative that the nurse researcher not only identify a philosophical framework that best guided the research study, but also choose a data analysis method congruent with the philosophical underpinnings (Stubblefield & Murray, 2002). Therefore, the Listening Guide, a voice-centered relational method, was used. The Listening Guide, a voice-centered relational method, is a process used to qualitatively analyze the extent of the intersection of social influences and experiences on one's conscious or "inner" self (Gilligan, 2003). The Listening Guide uses elements of music such as resonance and rhythm to extrapolate and understand the "voice" of the speaker. It is this voice that gives insight into the realities and truths of the speaker (Gilligan, Spencer, Weinberg, & Bertsch, 2006). Concerning the research question, "What is the lived experience of women living with HIV regarding intimate relationship power and reproductive decision-making," the Listening Guide unpacked the women's multifactorial experiences, allowing personal testaments to be coded many times before a final analysis was presented. Coding testaments multiple times ensured the complexities of the women's experiences were not reduced to a single static category (Gilligan et al., 2006).

Research studies that use theoretical frameworks and research methods that are complementary to one another allow the truest essence or "commonalities" of the lived experience to come forward to then be described in a scientific manner, which affords transferability to other individuals in similar situations (Lopez & Willis, 2004). This qualitative descriptive phenomenological research study provided an opportunity for WLWH to tell their experiences, first-hand, regarding subject matters that are intimate but important enough to be told. Qualitative descriptive research designs provide a breadth of scientific data that can be influential in how health care practices are implemented and what services are further needed (Magilvy & Thomas, 2009) to assist WLWH.

Research Sampling

Qualitative research sampling methods involve nonprobability sampling. This method results in a more thoughtful consideration of which individuals to select as participants in the study; participants are usually chosen based on their experiences. Sampling methods that involve randomly selecting individuals to participate in research studies inhibit the "most effective way" to explore specific phenomena about human behavior and individuals' truths (Marshall, 1996).

Sampling for this qualitative descriptive phenomenology study included purposive and snowballing techniques, as these sampling techniques have been shown effective given the research methodology and population under investigation (Bonevski et al., 2014; Streubert & Carpenter, 2011). Initially, participants were recruited via purposive sampling; participants were then asked to refer other WLWH to the nurse

researcher. The nurse researcher then determined if the referred women were appropriate for the study. Because there was no set number to define an adequate qualitative sample size, interviews continued until the phenomenon was understood, and no new truths were revealed. Therefore, sampling and interviewing were completed when the data became saturated (Braun & Clarke, 2013).

Participant Eligibility

In order to be eligible to participate in the research study women must have met the following inclusion criteria: (a) be between18 and 44 years of age, (b) biologically female, (c) self-identified as HIV-positive, (d) read and speak English, and (e) in a primary relationship with a male significant other. Exclusion criteria: women in menopause. The age range, 18–44 years old, and biologically female were inclusion criteria because these women were of an age where they could give informed consent and within reason of still being in their reproductive years of life. Being biologically female was imperative as this study aimed to understand female reproductive decision-making. Being able to read and speak English was imperative as consent forms were in English, and the nurse researcher was only fluent in English. Interpreter and translator resources were sought out; however, these services were unavailable to the nurse researcher. Being in a primary heterosexual relationship was pertinent as the nurse researcher was interested in power dynamics that existed among males and females and reproductive decision-making factors that impacted pregnancy desires and intentions. Women who were in menopause were excluded, as reproductive decision-making was a part of the research question and these women had no control over the cessation of reproductive

decision-making. However, women who had undergone permanent sterilization were not excluded from the study because the nurse researcher wanted to understand their reproductive decision-making process regarding sterilization.

Setting and Participant Recruitment

Participants were recruited from infectious disease clinics and case management facilities in two urban cities in North Carolina. The nurse researcher asked identified staff members at each site to distribute flyers and invite eligible women to participate in the study. Flyers were posted in common areas and examination and laboratory rooms. Once participants contacted the nurse researcher and were selected to participate in the study, the nurse researcher ensured that there were spaces available to conduct private interviews at each recruitment site. Participant recruitment continued until data saturation occurred.

Ethics and Human Rights

Before sampling and data collection commenced, the nurse researcher completed the University of North Carolina at Greensboro's (UNCG) Institutional Review Board (IRB) procedures. Depending on where participants were recruited, an additional IRB process was necessary. The notice of IRB approval and letter of support from recruitment sites are attached as appendices. Eligible participants were provided a hard copy of the consent form to keep for their records. The nurse researcher read the consent form aloud, and participants were asked if they had any questions and/or concerns prior to beginning the interviewing process. A small gift card was provided to participants after completing the interview in appreciation of their time.

Data Collection Process

Bracketing

The nurse researcher used a Husserlian phenomenological approach during the data collection process, therefore implementing bracketing, which entailed setting aside personal beliefs and ideas regarding the phenomenon (Richards & Morse, 2013). To effectively bracket and capture the true essence of what was being communicated, the nurse researcher frequently reviewed her presuppositions during the data collection and analysis process. The nurse researcher also met frequently with the qualitative experts on her committee to make sure data were being described accurately, according to the transcripts (Hamill & Sinclair, 2010). The following were explored and identified as personal presuppositions and ideas derived from reviewing the literature as it pertains to WLWH, their intimate relationship power, and reproductive decision-making:

- WLWH are ashamed of their diagnosis and do not want others to know about their seropositive status.
- WLWH may want children but have many uncertainties about their future.
- WLWH have less power in their relationships because of their seropositive status, especially if their male partners are seronegative.

Collection of Data

To keep with the essence of a qualitative descriptive phenomenological research design, the nurse researcher conducted unstructured, one-on-one, and open-ended interviews using an interview guide with a minimal number of prompts. Prompts were only used if necessary and were determined during the first interview. Participant

interactions lasted approximately 45 minutes. The interview guide is attached in the appendix section.

Data Management

Each participant completed a demographic form and participated in an interview in a private area. The nurse researcher used pseudonyms when explaining the data findings. The participant contact list was in paper format, locked in a filing cabinet in the nurse researcher's home office; the contact list was not linked to the pseudonym. Audiotapes and transcripts were placed in BOX.uncg.edu, which is a secure server (password- and firewall-protected). The nurse researcher destroyed the audiotapes with ERASER once the transcripts were checked for accuracy and reviewed by the committee chair at the end of data collection.

Procedure for Data Analysis

The interviews for this qualitative descriptive phenomenology study were analyzed using the Listening Guide, a voice-centered relational method, developed by Brown and Gilligan (1992). As described in Gilligan et al. (2006), the first step in data analysis using the Listening Guide was multipart and was called "listening for the plot." During this phase of the data analysis process, the researcher, whom Gilligan et al. (2006) refer to as the listener, was listening for the plot and their overall feelings regarding the interview's subject matter. To identify the plot, the listener has to have a thorough understanding of the whats, whos, whys, and wheres of the situation. To identify the listener's overall feelings, the listener was to notate images that were conjured, metaphors, and common themes that arose. Contradictions and omissions were written

down in field notes. All of these notations were considered given the social and cultural context of the listener and participant.

The second step in the Listening Guide is "I" poems; this step entailed focusing on the participant's use of the word I. When listening for the use of this first-person pronoun, the listener aimed to identify "distinct cadences" and "rhythms," along with trying to understand how the participant uses the word I in regard to themselves. When the listener was able to isolate cadences and rhythms along with understanding how the participant was speaking of themselves, the listener established an intimacy that built a foundation conducive to being able to accurately describe and personify what was being related by the participant (Gilligan et al., 2006).

In order for the listener to be able to construct I poems, there were two important steps. The first step was to identify all first-person statements, along with verbs and other important words. The second step in constructing the I poem was to keep the statements with the first-person, verbs, and other imperative words in the order in which they were transcribed; each statement should be written on a separate line, mirroring a poem. The arrangement of the statements in this manner is said to ultimately depict the participant's most inner thoughts (Gilligan et al., 2006). Here is an example of an I poem from the current study:

I have been knowing you for six months now I felt embarrassed.
I seriously had to think five times about what if I pass it to him.
I wanted to make sure I knew when I first got diagnosed.
I was like "Oh God" I brought a child into the world
I didn't know if she was infected or not.

The third step of the Listening Guide involved listening for "contrapuntal voices;" contrapuntal voices allowed the listener to analyze what the participate was communicating as it related to the research question. This step of the Listening Guide allowed for the essence of the lived experience to prevail. Listening for contrapuntal voices entailed listening (reading) to two or more statements in tandem. The assumption was that each statement had its own rhythm and "melodic curve". Listening to the statements within this particular musical context, combined with having listened to the plot (Step 1), and the construction of I poems, allowed the listener to understand the "multiple facets" of the participant's experiences. It important to note that in Step 3 of the Listening Guide, the listener was listening/reading the transcribed interviews multiple times. With each read of the transcript, the listener was paying close attention to one specific aspect of the participant's experience, or the main voice "within the person's expression" regarding their experience (Gilligan et al., 2006).

Finally, Step 4 of the Listening Guide, as described by Gilligan et al. (2006), was to compose an analysis; by this time the listener has read the transcripts a minimum of four times, made notes, and summarized findings with each read thus, leaving an "audit trail." It was during this step in the data analysis process that the lived experience of each participant was described as it related to the research question. The researcher reflected on what was discovered and how she reached this understanding. The researcher must understand that it is during this step in the data analysis process that the research question and/or prompts may need "modifying" in order to capture the purest essence of the phenomenon under investigation. After using the Listening Guide to analyze the data, the

findings were disseminated in a “rich” (Streubert & Carpenter, 2011) academic-style format.

Trustworthiness and Rigor

To promote trustworthiness and rigor, the nurse researcher addressed factors that ensured credibility, transferability, dependability, and confirmability (Streubert & Carpenter, 2011). To ensure credibility, the nurse researcher conducted informal member checks. Informal member checking was done by asking participants for “clarification” and/or “elaboration” during the interview process when it was deemed necessary (Sandelowski, 1993).

The nurse researcher ensured transferability by making sure there was a detailed account of sampling procedures, participants’ demographics, data collection methods, data management, and analysis process. Dependability was upheld by space triangulation. Space triangulation was the collection of data at various recruitment sites. Lastly, confirmability was completed by informal member checking, ensuring transferability, and dependability which resulted in an audit trail. The audit trail serves as documentation of the research process so that others can replicate the study (Streubert & Carpenter, 2011).

Summary

This chapter discussed the methods that were implemented for this qualitative descriptive phenomenological research study. The importance of having a philosophical framework and data analysis process that were complementary was highlighted. Research sampling which included participant eligibility, setting and recruitment, and ethical and

human rights were outlined. The data collection and analysis processes were explicated. Lastly, the nurse researcher's efforts to ensure trustworthiness and rigor were well-documented.

CHAPTER IV

RESEARCH FINDINGS

Introduction

HIV affects women in various ways that are gender-specific. In addition to the biological consequences of having the virus, there are important psychosocial factors that are present for women living with HIV (WLWH). Psychosocial effects for WLWH involve how they cope with the virus, maintain relationships, navigate disclosing their HIV status, and deal with the stigma associated with having the virus. As there are gender-specific effects of living with HIV, there is an increased need for more research that investigates the power dynamics between WLWH and their male significant other, specifically those living in the southern part of the United States. The southern region of the United States is suffering the "greatest burden" of increasing HIV rates and adverse health-related outcomes compared to other regions in the United States. Indeed, the south is now the new HIV epicenter (CDC, 2016). There is also a need for more qualitative studies that examine how power dynamics between WLWH and their significant others impact reproductive decision-making. More qualitative data will provide the richness needed to support quantitative and interventional studies that also aim to improve sexual health outcomes in WLWH (Robinson et al., 2017). The purpose of this research study was to develop an understanding of the lived experience of WLWH, with a specific focus on intimate relationship power and reproductive decision-making. Investigating the

research question, “What is the lived experience of women living with HIV regarding intimate relationship power and reproductive decision-making” entailed interviewing nine women living with the virus. Audio-taped interviews were transcribed verbatim, and transcripts were analyzed using a voice-centered relational method, which aimed to isolate and understand the voice of the speaker (Gilligan et al., 2006). Using the voice-centered relational method to analyze the transcribed data resulted in 42 codes, which were collapsed into 19 categories and then three themes. This chapter presents the participants and then describes the findings of the research study.

Description of Participants

Nine WLWH from two urban cities in North Carolina were interviewed for the study. The face-to-face interactions and tape-recorded interviews lasted approximately 45 minutes each. The women were recruited from case management facilities and health care provider offices. Recruitment was slow. The nurse researcher worked diligently to recruit participants over 20 months. Data saturation was reached after interviewing nine participants. The majority of the women who participated were African-American. The age range of the women in the study was 18–44 years old. The majority of women in the study had completed at least the 12th grade and had been living with HIV for at least 7 years. See Table 1 for a summary of participant characteristics.

Table 1

Women Living with HIV Study Characteristics (*N*=9)

Characteristic	*n*	Percentage (%)
Race/Ethnicity		
White/Caucasian	2	22.2
Black/African-American	7	77.8
Age (years)		
18-25	2	22.2
26-31	3	33.3
32-39	3	33.3
40-44	1	11.1
Highest level of Education		
Less than 11th grade	1	11.1
12th grade	5	55.6
More than 12th grade	3	33.3
Years living with HIV		
1-3	1	11.1
4-6	2	22.2
7 or more	6	66.7
Number of Children		
None	3	33.3
One	3	33.3
Two	3	33.3
Virally Suppressed		
Yes	7	77.8
No	1	11.1
Unsure	1	11.1
HIV Effects Desire for Children in the Future		
Yes	3	33.3
No	6	66.7

Table 1

Cont.

Characteristic	*n*	Percentage (%)
Likely to Disclose Your HIV Status		
Very Likely	6	66.7
Somewhat Likely	3	33.3
Partner's HIV Status		
HIV-negative	8	88.9
Unsure	1	11.1
Type of Birth Control		
Pill	3	33.3
Depo Shot	1	11.1
Tubes Tied	1	11.1
Condoms	1	11.1
Hysterectomy	1	11.1
Tubes Tied and Condoms	1	11.1
Does Not Use Birth Control	1	11.1
Diagnosis Occurred		
Before having children	3	33.3
After having children	2	22.2
During pregnancy	2	22.2
Perinatally	2	22.2

Getting to Know the Participants

Aubrey. Aubrey is an African-American woman who is between the ages of 32 and 39 and had less than 11 years of education. She has been living with HIV for 4–6 years. Aubrey has a boyfriend, who is HIV-negative, whom she met in a recovery meeting. They have been dating for 2 years. Aubrey's boyfriend was accepting of her diagnosis when she initially disclosed her HIV-positive status to him. Aubrey and her boyfriend are no longer sexually active because her HIV viral load is elevated. She wants

her viral load to be undetectable before having sexual intercourse again with her boyfriend. Aubrey has two children from a previous relationship. She found out she was HIV-positive after she had her first child; both children are HIV-negative. She does not have custody of her children, although she wishes she did. Aubrey has always wanted only two children, and now that she has two, she does not want any more children.

Aubrey became very tearful several times during her interview. The first time was when she spoke about her second pregnancy and admitted that she does not know who fathered her second child. The other times when Aubrey became emotional were when she spoke about how her family treated her once she disclosed her HIV status. Aubrey stated that her family "separated" themselves from her. The HIV stigma shown by Aubrey's family was "hurtful." Over time Aubrey has managed to find the emotional support she needs to cope.

Bianca. Bianca is an African-American woman who is between the ages of 26 and 31 and has more than 12 years of education. She has a boyfriend who she has been dating for two months. Her boyfriend is HIV-negative and is aware and accepting of her HIV-positive status. Bianca was a teenager when she had a child from a previous relationship. She found out she was HIV-positive while pregnant but believes she was perinatally infected with the virus. She loves children and wants to have more children in the future; however, she wants to be married first.

Bianca was a child when both of her parents, who were divorced at the time, died. She was told they passed away from cancer, but later found out that they passed away from complications related to AIDS. Bianca lived with her stepmother after her

parents passed away. Throughout Bianca's life, she was frequently hospitalized. Her stepmother told her she had sickle cell disease, and that was why she was often sick. As an adult, Bianca was diagnosed with HIV and suspected that her stepmother had concealed her HIV-positive status from her. Bianca remembered a time when she was in elementary school, and she and her sister got into a fistfight at their home. Bianca ended up with a bloody lip and spat blood on the bed. Instead of washing the bedsheets and wiping down the bed, her stepmother threw the entire bed away. It was moments like these that lead Bianca to believe that her stepmother was aware of her HIV-positive status. Bianca feels betrayed by her stepmother and no longer has a relationship with her.

Candace. Candace is an African-American woman who is 18 years old and is in high school. Candace has a boyfriend who is HIV-negative; they have been dating for one month. Candace was perinatally infected with HIV. Being in high school and HIV-positive is difficult for Candace because she has a hard time knowing how to disclose her HIV status to her partners.

Candace was a virgin up until she met her current boyfriend. Their relationship started "bumpy" because Candace did not disclose her HIV status until after they had sexual intercourse. Her boyfriend was upset and broke up with her, accusing her of giving him HIV. Candace doubted she gave him HIV because they used a condom during sex. Her boyfriend later got tested for HIV, and his results came back negative; Candace was relieved. Soon after, Candace and her boyfriend were dating again. Candace shares that she takes her birth control pill irregularly because she often forgets to take it. She would like to have children one day but wants to wait until she is older.

Danielle. Danielle is an African-American woman who is between the ages of 18 and 25 and has 12 years of education. Danielle was perinatally infected with HIV. Danielle has a twin sister who is HIV-negative. Danielle often wonders why she was the one infected with HIV and not her sister. Both of her parents are deceased.

Danielle has a boyfriend who she has been dating for over a year. Danielle is not aware of her boyfriend's HIV status but assumes he is HIV-negative. She has not disclosed her HIV status to her boyfriend because she is not sure how he will respond. Danielle and her boyfriend have never been sexually active. Danielle stated that her boyfriend is willing to wait until she is ready to have sex. Once she is financially stable, Danielle would like to have at least four children.

Ellen. Ellen is a Caucasian woman who is between the ages of 32 and 39 and has more than 12 years of education. Ellen found out she was HIV-positive while in a detoxification program; she has been living with the virus for 4–6 years. She recently separated after being married for 13 years. She currently has a partner who she has been dating for about a month. He does not know of her HIV status, although they have been sexually active without condom use. Ellen currently has two children, and after having had a hysterectomy does not plan or want to have any more in the future.

Farrah. Farrah is a Caucasian woman between the ages of 26 and 31 and has more than 12 years of education. Farrah was dating a man who was using intravenous drugs and tested positive for HIV. When Farrah was 18 years old, she went to the health department to get tested and found out she also was HIV-positive. One day, Farrah was on the phone telling someone about her HIV status when her mother overheard her

speaking. Her mother proceeded to tell the rest of Farrah's family about her HIV status. Farrah has one child and wants to have one or two more in the future.

Farrah currently has a boyfriend who she has been dating for two months. When Farrah disclosed her HIV status to him, she stated he was "OK" with her status. Farrah's boyfriend is HIV-negative. Farrah felt better once she was able to disclose her HIV status to her current boyfriend and realized that he would be accepting of her. In the past, she had encountered men who were not as accepting of her HIV status, and, therefore, did not want to pursue a relationship with her. Farrah admits that it can be lonely living with HIV.

Gina. Gina is an African-American woman who is between the ages of 40 and 44 and has 12 years of education. She has been living with HIV for 7 or more years. She discovered that a previous sexual partner had died from complications related to AIDS, which prompted her to get tested. She was devasted when she learned she was HIV-positive. She believed her previous sexual partner was aware of his HIV status but withheld this information from her. Not wanting others to have a similar experience as she did, Gina always made it a point to disclose her HIV status to partners.

Gina is currently engaged to be married. She and her fiancé have been together for 15 years. Gina's fiancé is HIV-negative and is accepting of her condition. Gina acknowledges that her fiancé and her family provide a great support system for her. Gina and her fiancé have one child together, and she does not want any more. Gina had a bilateral tubal ligation in order to avoid having more children.

Heather. Heather is an African-American woman who is between the ages of 32 and 39 and has 12 years of education. Heather was perinatally infected with HIV, although she did not find out about her HIV status until she was in high school. At that time, Heather's mother became very ill, and her mother's doctors ran several tests to determine the cause of the illness. The last test they performed was an HIV test, which came back positive. Heather was then tested and found to be HIV-positive. Finding out she was HIV-positive was very difficult for Heather as she felt her once bright future was beginning to dim. Heather stated that she soon realized that she would not be able to do all the things she had hoped to do with her life.

Heather has a boyfriend who she has been dating for 7 years. Her boyfriend is HIV-negative and is accepting of her diagnosis. Heather has two children from a previous relationship. Heather admits that her first pregnancy was unintended; she was using Depo-Provera at the time for birth control. Heather's second pregnancy was the result of her not taking specific measures to prevent a pregnancy from occurring. Heather did not want to have any more children and underwent a bilateral tubal ligation procedure.

Ivy. Ivy is an African-American woman between the ages of 26 and 31 and has 12 years of education. She has been living with HIV for 3 years. Ivy found out she was HIV-positive when she had a miscarriage. Ivy stated she was in shock when she heard the news. After receiving her HIV diagnosis, Ivy immediately called the mother of the man who she thought was responsible for giving her HIV, to inform her about her HIV-positive status. Ivy has had a very difficult time keeping her HIV status confidential. Ivy believes someone she knows, who works in health care, read her medical records, and

began spreading information around the community and social media about her positive HIV status.

Ivy recently broke up with her boyfriend because he gave her chlamydia. Ivy feels that because she is HIV-positive, her boyfriend at the time did not respect her. Ivy is unsure about her ex-boyfriend's HIV status, although she thinks he is HIV-negative. Ivy does not have children but hopes to one day have children.

Themes

From the voices of these women participants, three major themes emerged. They are: I Have My Tribe, I Have the Power, I am HIV-positive, but I am Normal, and I am Informed.

Theme 1: I Have My Tribe

The first major theme that emerged from the voices of these women is, I Have My Tribe. For many WLWH, receiving the news that they are HIV-positive was devasting. Living with the virus, whether contracted perinatally or later in life, can mean that there are adjustments that must be made in order to live a healthy life. Often, adjusting and managing life with HIV entails having a sound support system in place to assist with challenges or to help with making important decisions. The voices of these women spoke of the importance of their support systems, which spoke to me as their "tribe." This tribe comes from various sources for WLWH. The two main groups that comprise these participants' tribe were (a) family and friends, and (b) their healthcare providers.

Family and friends. Most of the women participants' source of support came from friends, family, significant others, and sometimes even colleagues. During the

difficult times in Aubrey's life, when she was dealing with rejection and stigma from being HIV-positive, she found support in her friends, church members, and boyfriend. Aubrey stated, "I do have friends and people that are on the same level that I am on and they can come with me and understand my disease, my strengths, my weakness. You know, my hobbies, they really care." Aubrey also shared her connection with her church members. Aubrey stated, "Yes, uh only people that I do go around, you know, is my church members." Aubrey's church members are a vital source of support for her because they treat her "normal."

Although Aubrey has found support in friends and church members, her boyfriend is her main source of support. When Aubrey was asked what it is like to be in a relationship with her current boyfriend, she immediately shared how he accepted and supported her through her journey living with HIV. Aubrey shared,

> You know, uh, but he accepted me for who I am. He didn't judge me or nothing. Uh, he makes sure I take my meds and sometimes he comes to the doctor with me. You know, he always asks me, "did you take your meds today?" I'm like, yeah.

Aubrey continued to share,

> And he is not trying to pressure me to do anything and I like that because he makes sure I take my meds, so that is letting me know that he actually cares about the both of us. Not just himself. You know? So, make sure I take my meds, make sure I have something to eat behind it, even if I am not in his presence, he will still call, he will still text. "Make sure you take your meds", sometimes I am still asleep. I am still in bed, so (starts laughing).

Although Aubrey has only been dating her boyfriend for a year, she commented on how it feels longer and why she is happy. Aubrey stated,

> Yeah, so it's, it's, it's, it's almost like I have been knowing him forever, even though it has only been like a year. But I am glad that I do have an understanding, I mean I am glad we do have the same . . . we have the same understanding. Because it is hard, there is a lot of people, I mean I have been going to meetings . . . people that are infected, and it is a lot of people out here, all they have is their self.

Candace spoke about how she has found the support she has needed to cope with living with HIV. Candace has disclosed her HIV status to four of her friends. Candace stated that their reaction to her HIV status was, "Good, like they still in my life to this day. I'm thankful for the four real true friends that I have, not these temporary friends who come and go." Heather also mentioned how a friend of hers has been a good source of support for her over the years, as she dealt with the reality of having to live with HIV. They have a 17-year-old friendship and Heather stated, "She's like my sister." Ivy, too, has a friend to encourage and offer her support when she needed it the most. Ivy shared,

> My friend, when it first went down, when he called me that night. I couldn't sleep and I called her and I was like what you doing, come over I got to talk to you. And when she first pulled up and got out and I just blurted it out and I told her, she was like "oh my gosh, it's ok, I got herpes." So, you know what I mean? It's like I told her and then she told me so it's just like that's another person that know. She's been helping me get through stuff and she's a very positive person. She goes to _____ (blank for confidentiality) you know, she gives me all types of positive everything.

When Danielle was asked why she maintains a relationship with her boyfriend, she stated, "Because he motivates me to do better and like if I'm stressing something, he

helps me through it." When Gina was asked to describe her fiancé, she stated he is, "wonderful." She shared how he supports despite her being HIV-positive. His response to her disclosing her HIV status was, "What is that supposed to mean to me?" Gina confirmed that this meant "He accepted" her diagnosis. Gina goes on to list her "Dad" and "Brother" as additional sources of support. Heather found much-needed support from her boyfriend. She shared this about her boyfriend, "He's nice, he's understanding, he's good to my kids. He's just an overall good guy. If I need somebody to talk to or if I need help with anything, he's there for me. Very supportive."

Bianca who works in the HIV community and has been able to find support amongst her colleagues. Bianca shared,

> Like um just this year I had a presentation at a group home I use to stay at when I was in foster care. And I told them. They had no idea . . . the right individuals knew my status 'cause they worked very close to me when I was living in the group home, but the rest of the people that worked there had no idea.

The support that Bianca got from her colleagues, after disclosing, has helped her. She stated, "I'm able to like speak my truth." Not only has working for an HIV activism group helped Bianca learn to speak her truth, it continues to motivate her to want to help others. Bianca is on a mission to provide support to those who are even more marginalized in the HIV community. Bianca has noticed a gap in the type of support available to certain groups living with HIV. She stated, "Because it's more common for the homosexual community to be receiving of HIV care and information and stuff. With the heterosexual, its more swept under the rug . . . I'm just trying to find ways to target the heterosexual community."

Health care provider support. Although many of the WLWH reported not seeing a counselor or attending structured support groups, eight of the women identified their health care providers as being a source of support during their journey with HIV. More specifically, six of the women recognized their health care providers as being a means of support when it comes to discussing their reproductive goals. Of the health care providers noted as a means of support, half were specifically identified as being infectious disease providers.

Aubrey stated that her doctors supported her decisions about pregnancy, always giving her the "choice" to make her own decisions. Ivy also shared how her infectious disease doctors are supportive of her and her pregnancy desires. She said, "My doctors here is all for pregnancy." Gina's experience with her doctors when she was pregnant was "great." Bianca knew the kind of support she needed from her doctor, and when she was not receiving the support she needed, she switched doctors. She stated,

> My doctor now was my physician, my primary doctor, and I asked her to be my HIV/AIDS and stuff. She was like, yeah. I go to her for everything. I love it. Cause I'm like, I use to go to ___ (blank for confidentiality) and I wouldn't be able to speak to that doctor the way I speak to my current doctor now. I was like . . . Like a one on one thing like I could call her and say something is not right. Can I come in and she'd be like "absolutely" because she knows my health is number one priority for me. If I start feeling something different and I know I haven't been doing anything but with one person, yeah. I'm going to go get checked out.

When Bianca was probed if her doctors support her and her decision to have children in the future, she responded, "Oh yeah. Oh yeah." When Candace was probed about her how she is treated by health care providers, she stated, ". . . Friendly, nice,

supportive" Ellen has had positive experiences with most of her doctors. She shared, "But my doctors for the most part are good. I've gotten lucky and found some that I really like." Ellen notices a major difference when she sees her infectious disease doctors, they take her seriously and do not "blow her off" like other doctors in the past have done. Ellen said this about her infectious disease doctors, "They are pretty good. I guess cause it's their specialty. It's not scary to them."

Theme 2: I Have the Power

The second major theme that emerged from the voices of these women is, I Have the Power. The findings from this study show that these WLWH have encountered difficult times throughout their journey living with HIV, especially as it relates to issues around HIV disclosure. Despite the difficulties regarding HIV disclosure in their pasts, most of these WLWH have still been capable of disclosing their HIV status to their significant others. After hearing the reasons why the WLWH chose to disclose their HIV status, data analysis revealed a connection between HIV disclosure and reproductive decision-making. The WLWH in this study demonstrated personal power; they were capable of disclosing their HIV status and making reproductive decisions. This feeling of power leads to intimate relationship power dynamics between the women and their partners, which has an impact on decision-making regarding sexual intercourse and reproductive decision-making. The theme of I Have the Power has four main categories: (a) disclosing is difficult, (b) disclosing is doable, (c) reproductive decision-making, and (d) intimate relationship power.

Disclosing is difficult. The voices of these WLWH women demonstrate that they have the power when it comes to disclosing their HIV status, although it often has been difficult. The women expressed their concerns and experiences with disclosing their HIV status to their significant others, including healthcare providers. The women reported being afraid of violence, betrayal, and being judged. They expressed fears of being rejected, not knowing how to articulate having an HIV-positive status, and not wanting to worry loved ones.

Danielle has been with her boyfriend for over a year and has not disclosed to him her positive HIV status. When asked why she is not comfortable disclosing her HIV status, Danielle shared, "Maybe I'm just scared what they going to say to me or react, are they going to hit me or something like that."

Two of the women discussed their experiences with feeling betrayed after disclosing their HIV status to previous boyfriends. For these women, betrayal was characterized by their significant other violating their privacy by telling other people about their HIV status. Bianca narrated how a previous boyfriend told his "whole family" about her HIV status. The mother of the boyfriend approached Bianca, screaming, "You'll give my child AIDS." Because of this type of reaction from the mother and other family members knowing of her HIV status, Bianca decided to end the relationship, putting her in the situation where she would have to move on and risk betrayal again when or if she discloses to another partner. Candace also has vivid memories of feeling betrayed after disclosing her HIV status to previous boyfriends. Candace shared how she

felt she could trust her previous partners only later to find out they would broadcast her HIV status on the internet, trying to "expose" her.

For WLWH, there can be much judgment around how the virus was contracted. Often people will assume that the woman must have been careless, having sex with multiple male partners. There is sometimes the perception that the woman is on drugs, often having sex with men to buy drugs. WLWH often think about how they will be perceived once they disclose their HIV status. Aubrey shared the mental preparation she underwent before disclosing her HIV status to her boyfriend. She stated,

> And when I first met him, it was kind of, with me having HIV, it was kind of hard for me to even come out and tell him. Because I even felt like, not embarrassed or ashamed but like okay**,** I am starting over a new life. How can I tell this person without being judged or without him spreading a rumor?

Bianca shared why she feels it is important to let new health care providers know how she became infected with the virus. Bianca stated,

> Oh yeah, 'cause I don't want people to assume that I'm out here spreading my legs for any and everybody. Cause If you tell them that you're positive the first thing that comes to their head is "oh she was sleeping with multiple people." No, I was born with it. It was a choice, it was a decision that I had no part of. So.

It is not easy disclosing your HIV status to someone with whom you hope to pursue an intimate relationship; finding the right words can be a challenge. When Candace, a high schooler, was asked to describe how her relationship with her current boyfriend has been, she stated that they started "bumpy." The relationship was tested when Candace disclosed her HIV status after having sexual intercourse with her

boyfriend, instead of telling him before they became intimate. When asked why she was not able to articulate her HIV status to her partner before becoming intimate, Candance stated that she wanted to tell her boyfriend she was HIV positive but did not feel she could get the words out. She said, “I was going to tell him before anything happened but I aint know how to put it in terms.”

Disclosure of one’s HIV status does not just involve informing intimate partners; it can also involve disclosure to family members. Disclosing to family members can be difficult, as these individuals are often the main pillars in the lives of WLWH. While WLWH cope with their diagnosis, they also worry about how their families will cope and react to hearing the news that someone they love is living with an “incurable" condition. Ivy became very emotional as she detailed why she has not disclosed her HIV status to anyone in her family. Ivy shared,

> It’s not right that I’m scared to tell them. But you know, I just don’t want them to go through the first initial reaction that I went through and that shock. Thinking that they are going to lose their daughter or sister or auntie, you know what I mean?

The fear of rejection made disclosing difficult for two of the participants. The women worried that their significant other would abandon them once they finally learned of their HIV status. Aubrey said, “I felt like he would just give me the boot.” Farrah shared her experience with rejection, “I’ve had situations in the past where someone was like, ‘no Girl bye’ and ghosted me.”

Disclosing is doable. While all of the women in this study have dealt with the difficulties of having to disclose their HIV positive status, especially disclosing to a

significant other, it is doable. Seven out of the nine women participants have been able to disclose their HIV status to their current partner, each having their motivating reasons.

The voices of the women demonstrated that various motivating reasons influence whether or not a woman discloses her positive HIV status to her partner. Aubrey detailed how trust and honesty are important factors in her relationship. Her desire to have a trusting relationship built on honesty leads her to disclose to her current boyfriend. Aubrey stated, "But in relationships there's trust. So, you know, I don't want to feel like I am hiding anything from him or, anything like that and with me being, with me having this uh, disease, I have to let him know."

Bianca spoke candidly about what motivates her to disclose her HIV status and the laws supporting her rights surrounding disclosing. Bianca shared, "I'm just like in ___ (blank for confidentiality) I'm undetectable so I don't owe you the rights of telling you, but I choose to tell you and I choose to tell the partners I have sex with." Gina's motivation for disclosing her HIV status to her fiancé was personal. Gina shared, "Cause that's how I got infected. A guy not telling me. A guy not telling me he had it. I said I'm not going to do that to someone else." Heather explained how being in a "long term" relationship with her boyfriend and getting to know each other made it less difficult to disclose her HIV status. Heather recalled her boyfriend's reaction when she finally disclosed her HIV status. She stated, "He was shocked, but I think by that time we had gotten to you know where we really had known each other for a while, and he was ok with it. He was ok with it." Farrah' s motivation for disclosing her HIV status to her partner had more to do with protecting her feelings, disclosing was a protective

mechanism. Because Farrah has had guys to "ghost," leaving never to be heard from again, she makes a point to disclose her HIV status promptly. Farrah shared during her interview, "I've gotten to the point now that I tell within the first week or two. So, if I do get ghosted, I'm not attached."

Reproductive decision-making. Intrapersonal reproductive decision-making is essential for overall reproductive health. Not only is having access to reproductive health care services necessary to achieve optimal reproductive health, but having the inner strength to make one's personal reproductive decisions is imperative. The voices of these women demonstrate that they have the power to make reproductive decisions.

The voices of the participants demonstrate that there are specific characteristics that WLWH possess when advocating for, and retaining power, in their reproductive plans. As previously described, a noteworthy finding regarding the women in this study and how they supported their reproductive plans had to with HIV disclosure. Interestingly, all of the participants who disclosed their HIV status to their partners were able to make decisions about their reproductive agenda in the future affirmatively.

Candace details her views on having children and what she would say to her boyfriend if he wanted a child now,

> I would be like, are you stupid? We are both still young, we are 18. You doing your music and going to school at the same time and I'm working and going to school basically trying to help my mom. When I get older, when I'm 19, I will start helping her pay her bills and stuff. We are still young. Let's wait until we are like 27.

Bianca wants two children in the future., However, she is very certain regarding the situation in which she will have more children. Bianca said, "I have told every dude that

I've dated that if it's not going to be life-long and you can't see me as a wife, yeah. There's no child coming out of me by you. No." Ivy wants at least one child in the future. She goes as far as to say if she got pregnant and her partner was not in agreement with the pregnancy, then "he's got to go. Because the baby is not going, he's going . . ." For Farrah, she wants at least one more child in the future. Farrah spoke to her and her boyfriend's desire to have children saying, "We both know we want kids, but not yet." For Aubrey, Gina, and Heather, the idea of having more children in the future, regardless of what their partners desire, is not up for debate. Aubrey only wanted a boy and girl, and now that she has both, she asserts, "I don't want no more." Gina, who never really wanted children in the beginning, was very sure that she does not want any more children. In attempts to avoid any unintended pregnancies, she reports having had a bilateral tubal ligation. When asked if she would consider reversing the procedure if her fiancé asked her to, she firmly stated, "I'm good. My son is four hands full. I'm good." Heather is also sure that she does not want any more children; she, too, has had a bilateral tubal ligation. Here are Heather's sentiments on having children in the future:

> I had told him that I had my tubes tied and stuff like that and he seemed like he was ok with it. But you know, like, I told him that if he feels like that's what he wants to do I'm not going to have any more children, I don't want to have any more children, you know.

Intimate relationship power. Either power equalities or inequalities characterize intimate relationship power. The power dynamics within the relationship determine who has the most decision-making authority. Decision-making authority is of interest to WLWH as it can impact overall reproductive decision-making and outcomes. Intimate

relationship power is also important to understand in WLWH as it can have an impact on intimate partner violence (IPV). Typically, women with less power are more likely to be subjected to IPV (Gaman et al., 2017). With this in mind, a significant finding of this study is that the voices of these women displayed power differentials that were in their favor, giving them decision making authority.

To get the overall essence of the power dynamics between the women and their male partners, a general question about decision-making was asked. In response to this question, eight of the women reported feeling like they that make the "big" decisions within their relationships. Keeping in mind the interview question posed, participants were then asked about decision-making regarding sexual intercourse. Of those women who were sexually active with their partner, most reported being an active participant in the decision-making process regarding sexual practices.

Aubrey was open about why she makes the decisions regarding the timing of sexual intercourse in her relationship. She shared,

> As far as sex wise, because I don't want to put him in any kind of . . . I don't want to jeopardize his life . . . You know, so and I know I protect both of us. 'Cause right now, I am not, I'm not undetected. So, I have to protect both of us, 'cause you know, this is his future and mine.

Heather stated that she also makes the decisions about the timing of sexual intercourse in her relationship. When asked what her partner would say if she stated she was not willing to participate in sexual intercourse, Heather stated, "He'd be ok. He's never pressured me to do anything. I've never ever felt pressure by him to be sexually active with him." Bianca stated that she makes all the important decisions in her relationship and also

expressed her views on condom use. She said, “I mean it’s not a choice he has. So I give condoms, like if you don’t put it on like, I’m not participating in that.” Bianca also went on to discuss how her health plays a part in her sexual decision-making. Bianca stated, “I had told him that I am undetectable, and I can’t transfer my HIV on to him or anybody else. And he wants to have unprotected, but no, I provide condoms.” Candace was a virgin when she and her current boyfriend first had sex; she stated it was a mutual and consensual decision. For Candance to have been a virgin at the time of intercourse with her boyfriend, she was very vocal about why she decides to use condoms. She explained it like she would if she was explaining it to her boyfriend, “Why would I put you in that risk of danger of living with this for the rest of your life when I have to go through it.” Also, Candace makes sexual decisions for her own personal reasons. Candace said, “I’m not trying to get pregnant” when she was asked about factors regarding condom negotiation. Although Candace is still in high school, she seems to have already formed a very strong opinion about her male counterparts and why it is her responsibility to insist on condom use in her relationships. Candace stated, “boys gonna be boys, and men gonna be who they are . . . and at a certain point in time they gonna want to have sex raw.” Gina gave input as to why she chooses to use condoms with her fiancé, although her tubes are tied and the chances of getting pregnant are low. Gina’s reason for using condoms extends beyond the concerns of pregnancy and has to do with protecting the health of her fiancé. Gina’s fiancé is HIV-negative; therefore, she feels it her responsibility to “protect” him.

Theme 3: I am HIV-positive, But I am Normal, and I am Informed

The third major theme that emerged from the voices of these women is, I am HIV-positive, but I am normal, and I am informed. The WLWH gave their accounts of what living with HIV is like for them. Many of the women went on to discuss their future reproductive plans, as women in general do. The women shared their knowledge regarding their health and how being HIV-positive impacts childbearing. Finally, the women gave closing remarks on what they would like for others to know about HIV. The three main categories for this theme that emerged from the voices of these women are (a) life with HIV, (b) educated, and (c) what society should know.

Life with HIV. When the majority of the participants were initially diagnosed with HIV, they experienced shock, devastation, betrayal, and an array of other emotions. However, as time progressed, these women came to understand their diagnosis and have gone on to live reasonably normal lives.

Ivy noted that living with HIV is just like,

> A normal day is really just a normal day. The only time I think about HIV is when I take my medicine. That's literally it. Wake up, normal. Eat breakfast, go to work. Communicate with everybody I normally communicate with. I'm fine. I'm totally fine. I'm not stressful, I'm not depressed. I'm really not none of those.

Ellen describes how her life has been living with HIV. She states, "It's really not a whole lot different, other than when I first got diagnosed it was like I felt like people looked at me weird, like they could see it was a label or whatever. But that dissipated. It's really not that different."

Other women also gave their responses to how HIV affects their life. Bianca stated, "I mean, now it doesn't have an impact at all." Danielle said, "It doesn't. Besides taking the medication, it doesn't . . . I don't feel like it do. I already know I got to take my medicine in the morning, and then go about my day." Farrah shared, "I've had it so long I don't really know anything different . . . it's an extra pill to take every day." Gina said, "It doesn't. Besides taking the medication, it doesn't." Heather shared,

> . . . I go about my daily activities like everybody else does. I think about it sometimes like say I might scrape my hand or something like that, and I have to worry about you know, cleaning up and getting band aids and stuff like that. But other than that it doesn't really affect me in anything that I do throughout the day.

Part of living a normal life for the women centers around their relationships with their children and their desire to have children in the future. Six out of the nine women have children, and they discussed their relationships with their children. Five out of the nine women also stated that they want children in the future.

Although Aubrey does not have custody of her children, she stated that their relationship is "good" and "It's the same, nothing has changed." Bianca shared what her relationship is like with her son, she said, "It's beautiful . . . The mouth is reckless but that's my baby. That's my baby, so. I had him at a very young age I made the decision to keep him . . . I made the choice to keep him and promised he would be loved."

Ellen stated that her relationship with her children is, "Fantastic. We've always gotten along. We are very close. We hang out all of the time, which is unusual for their ages." Farrah shared her relationship with her child. She said, "We're very close. He's a

mama's boy. He's a mess." Gina and Heather stated that their relationships with their children is "good" and "great."

Educated. Despite varying ages and levels of education, these WLWH are aware of their health and how to manage their health while living with HIV. They are educated about the risks associated with transmitting the virus to their partners and/or unborn children. Aubrey detailed how taking HIV medications plays a major role in her overall health once she accepted her HIV-positive status. She stated,

> You know, I am satisfied, and I am actually complete. Now that I do know that I am HIV positive, I would rather know, than to not know. And to be sick for years and years and years and to not know that without any medication. So, I am glad that there is medication out here that I can take. So, you know, it's not like they say, there is no cure for it. Okay, if there is no cure for it, then why you all have medication.? To help me live longer. Why do you have medication? To keep me stronger. To keep me going, you know. So, there is a cure, it might not be a full cure but to me that is my cure. You know? Yeah, so I have to take my meds every day . . . this is my cure.

Bianca summarized her health, stating, "So even though I'm positive, I'm very healthy. I don't have anything else . . ." Bianca goes on to explain how she maintains her health, she stated,

> So, I schedule taking my meds between I give myself a timeframe between 2 PM and 4 PM. So, to remain or stay undetectable I take my meds at the same time every single day. So, If I'm busy or I lose track of time or whatever I try to take it either . . . close to 5 or 6:00 but I still get my meds in.

Although Bianca considers herself very healthy, she is aware that certain factors must be considered when she is provided health care. Bianca shared her communication with health care providers. She said, ". . . the first thing I tell them is, I was born with HIV. So,

they know to care for me differently than a negative person." Candace, although still in high school, understands the importance of maintaining her health. Candace said, "Living with HIV is nothing to play with. You got to take care of yourself and everything, make sure that everything is healthy and stuff."

Some of the women explained how their overall good health has made spreading HIV to their sexual partners virtually impossible. Bianca recalled a conversation she had with her boyfriend about HIV transmission risks. She said, "I had told him that I am undetectable, and I can't transfer my HIV on to him or anybody else." Ivy also talked about the likelihood of her spreading HIV. She stated, "Yeah, because they don't know that I can't pass it to nobody. I mean, I take my meds daily, so." Ellen recently found out that she, too, cannot transmit HIV to her partners. Ellen said ". . . Like I didn't know until not too long ago that as long as your numbers are below what is it, 200? Whatever the threshold is for being detectable, you can't even transmit it." Ellen proceeded to discuss how not being able to transmit HIV to her partner, influences whether she discloses her HIV status. She said, ". . . Because I wouldn't have had sex with someone and not told them without knowing that . . ."

The women discussed the impact of HIV on pregnancy and their future children. Aubrey shared her knowledge of pregnancy and having HIV. She said, "But as long as when you are pregnant, or when you think about having kids. As long as you are taking your medication, like daily, without missing any, you are fine." She also added, ". . . but you have to eat right and that's just about it, you know?" Bianca discussed her health and what her doctor thinks about her having children in the future. Bianca explained, "All my

labs have been undetectable like, no other STDs or STIs or nothing like that. I'm still on my meds, go to my doctor's appointments and yeah she says it's very possible for me to have another child . . ." Although Bianca knows that having children in the future is possible, she also knows that there could be certain complications. Bianca explained the complications she experienced in the past as a result of being HIV-positive. Bianca shared,

> Because an HIV positive female, I guess once you start the delivery process your . . ., I can't explain it well. But the immune system completely shuts down. I started my process like 8 AM that Friday morning and I had a fever from there on and the doctors were unable to break the fever. They gave me multiple meds, they did everything. And my fever was like coma, yeah. It was a possibility that I could have fell into a deep coma, it was 105. Yeah. So that is what scares me 'cause we're considered as high risk as soon as we get pregnant.

Danielle is informed about how HIV impacts having children in the future. She said, "I mean I know I could have kids that won't come out with HIV and if I do have kids that come out with HIV it's fine. I have been raised with HIV and I'm healthy, so they can be healthy too." Danielle shared where she got her knowledge from; she said, ". . . I started going to ___ (blank for confidentiality) and stuff and I learned more about having kids living with HIV and stuff." Farrah is also informed about how HIV impacts having children in the future. Farrah shared, "I've always wanted to have more kids. But technology is so advanced now, and as long as you're undetectable it's less than a 1% chance of transmitting it to your baby."

What society should know. The women were all asked at the end of their interviews if there was anything else that they wanted to share with the public regarding

life with HIV. The voices of these women concerning what they would like society to know are shared next. Aubrey said, “I love my life. And I loved my life before I got infected. So, for me nothing has changed. It’s just a sickness, it’s a disease. So . . . You know?” Bianca shared,

> I mean, education is key. I mean, before I was diagnosed, I was one of those ignorant kids. Like if I saw someone with bumps on their arms or on their hands and face or whatever. I would say “well that person has AIDS” but now that I know the history of HIV/AIDS and I can educate. I just had a presentation today about HIV and pregnancy at my social work class. They were amazed at the facts. So I’m like, the CDC brought this information out in the 80s about HIV only being a gay disease and HIV being a death sentence and no, it’s no longer like that. There are medications, we are so close to a cure but we are so far. So, its all education. You have to be able to receive the education that is given to you and take it to heart. Don’t be ignorant about it. Someone living with HIV is not purposely. Cause I also told them about the law that was passed in___ (blank for confidentiality). An HIV positive, undetectable individual is no longer required to disclose their status.

Candace wanted others to know “HIV is not going away. There is no cure. We just got to not let the negative stuff that people say about you on social media or anything affect what you got going on right now. Just block them any type, block them out of your life.” Ellen stated, “Basically, it’s not as scary as people think it is. Especially the older generation, who grew up, it’s a death sentence, or that it’s over, that has changed.”

Farrah shared, “That it’s not the death sentence that everyone thinks it is. You can still live a life, a good life. As long as you take your medicines and follow doctor’s orders . . . I’ve had it for over ___ years (blank for confidentiality) and I’m still doing great.” Heather said, “I mean, it’s not as bad as people make it out to be. It’s not something that

you can get as easily like if you catch a cold. You know, I can't sit and talk to you or you drink after or off of something that I've had, and you catch it."

Summary

The data obtained and conclusions reached from this study resulted from nine in-depth interviews. The nine WLWH participants had diverse ages, relationship status, and childbearing status. A description of the participants was provided for the reader to understand better who these women are as individuals. Collectively, the women identified and used nontraditional means for emotional support such as their tribe, which consisted of family and friends and health care providers. Therefore, the women were more likely to have disclosed their HIV status to their significant other, which demonstrated personal power. This personal power was then manifested as favorable intimate relationship power, which involved the women being active participants in their reproductive decision-making process (see Figure 1). The next chapter discusses these themes concerning the current literature. Implications for nursing education, practice, and research are also presented.

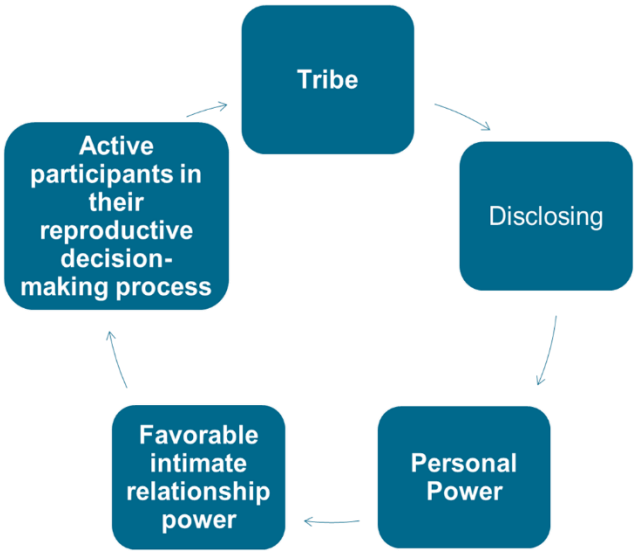

Figure 1. Summary of Themes.

CHAPTER V

DISCUSSION

Introduction

This qualitative, phenomenological study aimed to understand the lived experience of women living with HIV (WLWH) regarding intimate relationship power and reproductive decision-making. In-depth interviews were conducted until data saturation was achieved. Data saturation was achieved after interviewing nine women from various settings. A voice-centered relational method, a qualitative analysis process, was used to identify thematic categories. The three themes revealed are as follows: (a) I have my tribe, (b) I have the power, and (c) I am positive, but I am normal, and I am informed. In the following sections, the nurse researcher discusses the study's research findings, implications for practice and future research, the limitations of the study, and the significance of the research.

Theme 1: I Have My Tribe

The first major theme that emerged from the voices of the women participants in this study is, I have my tribe. *I have my tribe* is metaphorically speaking of the idea that WLWH have been successful in identifying core individuals in their lives who can be a sound source of emotional support. Often in the literature, there are details regarding the effectiveness of attending support groups for WLWH as it relates to the impact that these groups have on specific and measurable health outcomes. The tend-and-befriend theory

of Taylor et al. (2000) emphasizes the importance of social groups consisting primarily of women and how these groups are instrumental in helping women cope with the adverse events that may occur in their lives. Support specifically for WLWH has often been described as taking place in a structured group setting with other WLWH or in an office with someone who has a professional degree. A research finding from Barnes and Murphy (2009) showed that WLWH may not always be the best source of support for other WLWH due to their lack of knowledge and their perceived stigmas. A few of the women from the current study have also been able to identify formal sources of support to help them along as they navigate life with HIV. Formal support has been available to these women in the capacity of counseling, recovery meetings, or case management. However, having a formal source of emotional support was not identified by the majority of the WLWH in this study.

The findings from this study challenge the main narrative regarding what emotional support looks like for WLWH. Emotional support can indeed come from social groups, other women who have shared commonalities, or psychologists or therapists. However, as this study shows, support can come from, for instance, an individual whom a WLWH has known since childhood, an ailing father for whom a WLWH is also the caregiver, a WLWH's health care provider, such as a primary care doctor or infectious disease doctor, or a WLWH's male significant other. Most of the women in this study could not identify a formal source of support when needing to cope with the challenges of their diagnosis; in fact, most reported being able to confide in a close friend or family members when in need of emotional support. The findings from this study regarding

sources of emotional support are consistent with the findings of Vyavaharkar et al. (2011) in that emotional support can come from an array of sources.

Along with friends and family being a source of emotional support for the women in this study, health care providers were supportive for most of the participants. The women's health care providers offered not only emotional support, but also provided expert support and recommendations for their reproductive plans. The amount of discussion reported by the women from health care providers in this study shows a slight increase from the amount of provider discussion and support in the Rahangdale et al. (2014) study. Although the current study did not differentiate whether the provider or patient-initiated reproductive conversations, one thought is that women learning to cope with their diagnosis are comfortable enough to identify personal sources of support and therefore feel empowered enough to engage their health care providers in conversations about their reproductive plans. Unlike the findings from previous studies by Barnes and Murphy (2009) and Cuca and Rose (2015), many of the women in this study did not experience the common and harsh reality of stigma and judgment from their health care providers when discussing their reproductive goals.

WLWH need the tools to identify the individual(s) in their lives who could be sources of support as they are navigating life with HIV. WLWH do not necessarily have to be a part of a structured support group to achieve specific health outcomes; having reliable individuals in their lives from whom they can seek support can be just as beneficial as the previously mentioned forms of support. Vyavaharkar et al. (2011) agree that it is not about the number of supports in the lives of those living with HIV but more

about the quality of those relationships that can have a profound effect on specific health outcomes in this population.

Theme 2: I Have the Power

The second major theme that emerged from the voices of the women participants in this study is, I have the power. The WLWH from this study provided detailed accounts about how difficult HIV disclosure is, reasons why they chose to disclose their HIV status, how they make decisions within the context of their intimate relationships, and their plans to have children in the future.

Disclosing is Difficult But it is Doable, and it is Empowering

Many variables make disclosing one's HIV status difficult for WLWH. One of the main reasons associated with the difficulties of disclosing is the ever-prevalent stigma that is associated with having the virus. HIV stigma is "negative attitudes and beliefs about people with HIV" (CDC, 2018, p. 1). Stigma, in general, can be categorized as enacted or felt. When WLWH experience felt stigma, it is the perception or fear of being discriminated against because of their HIV status. When WLWH encounter enacted stigma, it is the actual experience of discrimination, as a result of being HIV-positive (Florom-Smith & De Santis, 2012; Scambler, 1998).

Consistent with the literature, all the women in this study experienced, enacted or felt stigma in some capacity as a result of being HIV-positive. The women spoke about how previous partners abandoned them once they found out about their HIV status. There was concern that there could be violence in the relationship if their HIV status was disclosed to their partner. Despite an increase in social awareness regarding the

transmission, treatment and prevention of HIV, there is still a significant amount of stigma experienced by those with the virus, as well as negative public perceptions of those who are HIV-positive (Clum et al., 2013; Dass-Brailsford et al., 2014; Maeri et al., 2016). As a result of stigma, disclosing that one is HIV-positive can be challenging. Women particularly have a challenging time disclosing their HIV status to their partners due to social stigma and uncertainty of their partners' reaction to their status (Barroso et al., 2014; Carter, Kraft et al., 2013; Clum et al., 2013). However, women in this study voiced motivating factors for disclosing their HIV status that were more personal versus being solely based on societal factors or partner dependent. Also, there were indications that the women were trying to prevent transmitting the virus to their seronegative partner; these findings are all aligned with the findings in Hoover et al. (2016). The women in this study who disclosed their HIV status to their significant others were taking measures to reduce the chances of transmitting HIV to their partners by negotiating sexual practices that involved abstinence until their viral loads were undetectable, or by using condoms during times of sexual intercourse.

Although the women in this study experienced stigma as a result of their HIV status being disclosed, most did not allow the stigma to disable them. HIV stigma did not discourage the majority of the women from disclosing their HIV status to their significant other. Clum et al. (2013) assert that WLWH disclose their HIV status based on the quality of their current relationship. Clum et al. (2013) imply that HIV disclosure is conditional or based on how well the relationship is progressing. In contrast to Clum et al. (2013), the findings of this study showed that the motivation for HIV disclosure had

less to do with the status of their current relationship, and more to do with the intrapersonal feelings of the women. The women participants chose to disclose their HIV status based on feelings of moral obligation, fear of rejection later in the relationship, and a value system rooted in honesty.

There is no denying that the women in this study have all had their fair share of turmoil and challenges as it relates to the shock of receiving an HIV diagnosis, the sequelae of HIV (such as having to disclose their HIV status), and the stigma that usually occurs in tandem with disclosure. Despite their challenges, these women have managed to persevere and take control of their lives. This perseverance is known as resilience. Resilience in the event of an HIV diagnosis often leads to empowerment (Dale et al., 2014). WLWH who are resilient and feel empowered can make decisions that suit them best. As evident by the findings in this study, WLWH who display resilience and empowerment can make autonomous decisions about when to disclose their HIV status, have sex, and their reproductive plans within their intimate relationships. In further support of the significance of this study's findings, it is imperative to highlight that just because WLWH are empowered in areas of HIV disclosure, sex, and reproductive decision-making does not mean they will be empowered in all aspects of their lives (Dale & Safren, 2018). The work done by health care professionals and advocates for WLWH should be aimed at empowering these women in the many other areas of their lives.

Intimate Relationship Power

Power within the context of an intimate relationship can be categorized as either process or outcome power. Process power is present when an individual can change her

partner's thinking. A display of outcome power is determined by who makes the final decision, impacting the other partner's actions (Farrell et al., 2015). This study did not focus on whether a partner's thought process was changed, nor did it delve into the specific, action-changing behaviors of partners. Instead, this study focused on the women's perception of their ability to make important decisions in their relationships. Generally speaking, almost all the women in this study stated that they make the "big" decisions within their relationships. Some stated that the decision-making process was a mutual effort, but that they nonetheless felt they had the autonomy to make certain decisions. When the power dynamics between the women and their significant others were examined further by assessing the women's ability to make decisions surrounding sexual activities, most of these women stated that they were active participants in the timing of intercourse and/or practices involving sexual intercourse, such as using condoms. This degree of self-efficacy, specifically in condom negotiation, displayed by the women is congruent with the findings from Buchmann (1997) and Raiford et al. (2007).

From the perceptions of the women in this study, the power dynamics favor them, supporting the notion that they are significantly influential within their relationships. The display of power favoring the women seen in this study may also explain why all the women who were asked about violence in their relationships denied being subjected to violence in their current relationships. Typically, when WLWH are at a power deficit in their intimate relationships, they are more susceptible to experiencing intimate partner violence (Gaman et al., 2017). According to Wingood and DiClemente (2000), women

are typically thought to be at a power disadvantage, often labeled as being "disempowered." It is the perpetuation of historical inequalities towards the female gender that demoralizes and continues to strip women of their power. The disempowering of women, therefore, puts them at risk of "physical exposures." Physical exposures may include physical and/or sexual abuse. These physical exposures cause behavioral risk factors that can ultimately impact their overall health. Wingood and DiClemente (2000) go on to further describe behavioral risk factors as the actions that lead to intimate partner violence and the inability to negotiate sexual practices. Despite having HIV, the women in this study are not disempowered. This study suggests that although women are living with HIV, they can be empowered, not experience intimate partner violence, and be active participants in decisions regarding sexual practices. When WLWH are empowered, their reproductive decision-making is more in line with their own personal reproductive desires (Sarnquist et al., 2014).

Reproductive Decision-making

Research that supports the evidence-based practices that impact the lives of WLWH is at the core of fundamental human rights for this population. WLWH are entitled to services and health care that are effective as they relate to these women's reproductive health outcomes (World Health Organization, 2017c). Research studies that examine the reproductive decision-making process that occurs within WLWH are imperative in order to gather the evidence to serve this population better. Reproductive health outcomes in WLWH can be partly attributed to each woman's intrapersonal decision-making capabilities. This study shows that when women are comfortable

enough to disclose their HIV status to their significant others, regardless of their partners' HIV serostatuses, those women can make statements with certainty when it comes to reproductive decision-making. During the interviewing process, the women were challenged with various scenarios, asking how they would respond to their significant others if the significant others' reproductive goals were different from the women's. The women gave similar answers each time, answers that were congruent with their initial responses. These findings are contrary to the findings from the study by Jones et al. (2016), which showed that a significant other's opinions regarding future pregnancy plans were impactful in the reproductive decision-making process of a WLWH.

Most of the women in this study gave a self-reported account of being virally suppressed. Interestingly, most of the women stated that being HIV-positive did not affect their decisions to have children in the future. The findings from this study are contrary to a previous study that showed that women's reproductive plans were heavily influenced by their HIV status (Amutah et al., 2016). Sowell et al. (2002) suspect that when WLWH reproductive decision-making is not impacted by HIV infection, it is personal beliefs regarding motherhood along with cultural norms that have more of an effect on reproductive decision-making.

Although most of the women stated that HIV does not affect their reproductive decision-making, a few of the women in this study were concerned about transmitting the virus to their unborn children. They were so concerned about transmitting the virus that they went as far as undergoing permanent birth control measures such as bilateral tubal ligation or hysterectomy; however, these women were the minority in this study. As

previously mentioned, most of the women spoke specifically about not being worried about transmitting HIV to their unborn children, while others spoke more generally about being well-informed about not being able to transmit the virus if they took their medications as prescribed and as long as their viral loads were low enough. One woman even gave statistics to support her rationale for pursuing motherhood. Most of the women were virally suppressed and not worried about transmitting HIV to their unborn children, but this does not mean that the women did not consider the possibility of transmitting HIV to their unborn children. It means that these women had been educated on the importance of adhering to their medication regimens and staying in the care of their health care providers. When WLWH are presented with the evidence surrounding reproductive matters, they are better equipped to give informed consent regarding how they personally want to proceed in making reproductive decisions.

Theme 3: I am HIV-positive, But I am Normal, and I am Informed

Thirty years ago, one would consider using the terms being HIV-positive and normal in the same sentence paradoxical. Due to the scientific breakthroughs that have occurred in the research and management of HIV/AIDS, individuals living with HIV can confidently use the word “normal” to describe themselves, as they are living healthier and longer lives. The majority of the women participants in this study have been living with HIV for 7 or more years, which has given them time to adjust to their new *normal*. Over the years, the women in this study have not only adjusted to their new identities, but they have become more informed about their condition.

Throughout their journey with HIV, the women in this study have had experiences that can specifically be attributed to having such a highly stigmatized condition. Despite these experiences often associated with having HIV, the women participants in this study have gone on to live reasonably normal lives. These women have come to terms with their positive HIV status and they do not allow the virus to have a major impact on their everyday lives. Most of the women mentioned how their lives are normal, and often the only time they remember they have HIV is when it is time to take their medications. Normal is categorized by the actions of WLWH in this study that tend to not differ much from women who are HIV-negative. As demonstrated by the findings of this study, these actions include being a part of the workforce, attending school, and managing their household. One action in particular that further normalizes these women is their role as mothers and the desire and intent to have children in the future. The majority of the women in this study are mothers, most of whom had children after their HIV diagnosis. For women in general, embarking upon motherhood is a critical factor in establishing their womanhood and fulfilling what they may feel are social norms and obligations (Smith et al., 2016); and for WLWH, this is no different. It is the reward of embarking upon motherhood that often gives WLWH the feeling and confidence to recognize that they, too, are normal (Barnes & Murphy, 2009; Kennedy et al., 2014). Society can be harshly critical of women who do not fit the typical mold of what a mother should look or act like (Connell, 1987; Kennedy et al., 2014; Wingood & DiClemente, 2000). Fortunately, the women in this study have found great resources for

support, including support from their health care providers, who serve as a buffer to the stigma associated with WLWH bearing children.

The women participants in this study who want and expect to have children in the future do so with the will and knowledge to keep themselves and their unborn children healthy. The findings from this study are congruent with the findings from Fletcher et al. (2016), supporting the notion that WLWH make reproductive decisions based on the knowledge they have and find to be reputable. Fortunately, the participants in this study have been in communication with their health care providers, which has been beneficial in providing them with a wealth of vital knowledge and confidence to help them with future pregnancies. As mentioned in the above section, WLWH are making reproductive decisions with informed consent, information that they have acquired as a result of being in care.

Although the women participants in this study are HIV-positive, they feel normal, empowered, and knowledgeable enough to make reproductive decisions. These feelings have led WLWH to want to send a message to society. Collectively, from the voices of the WLWH from this study, that message is, I love my life; so, educate yourselves and know that HIV is not a death sentence, and always press forward even amid negativity.

The findings from this study are aligned with the current social climate in the United States; times are continuing to change for women in the United States. This study debunks many myths that women are not active participants in their reproductive journeys. As women continue to embark upon motherhood, they are concurrently pursuing formal education and careers, which is a detour from historical societal norms.

As women, including WLWH, are taking on more responsibilities outside of the home setting, there has been a noticeable shift in the attitudes of women regarding what they will or will not tolerate when it comes to their personal lives. Women are witnessing other women speaking up against unfair work wages, unwanted sexual advances, such as the Me, Too Movement, or the inability to rightfully make certain reproductive decisions. Not only are WLWH among those who are advocating for fairer treatment and equal rights for women, but they are among the millions of other Americans who have taken notice of what it looks like when women individually and collectively find their voices and demand change. As a result of women around the country voicing their concerns and advocating for themselves, it should be no surprise that WLWH are doing the same when it comes to matters regarding their intimate relationships.

Summary

As a result of in-depth interviews and data analysis, connections have been identified and discussed in this chapter. HIV has become more of a chronic condition, with health care professionals having a better understanding of how to manage the virus, resulting in improved health outcomes. As a result of better management of the virus, it seems as though certain aspects of the lives of WLWH are improving. WLWH are identifying key individuals in their lives and assembling their supportive networks. As a result of having influential sources of support, the women are coping with their condition, capable of disclosing their HIV status to their significant others, and, therefore, demonstrating personal power. This feeling of power led to favorable intimate

relationship power dynamics between the women and their partners, which had a positive impact on sexual and reproductive decision-making.

Implications for Practice

The findings of this research project have several implications for practice. For those professionals who work with WLWH, they must take the time to help WLWH understand the importance of identifying key people to be a source of support. Having already formed personal and meaningful connections with individuals who can provide emotional support as WLWH deal with issues surrounding their HIV infection is shown to be beneficial for many areas of these women's lives. Not only is encouraging these types of supportive relationships beneficial to the health of WLWH, but it is significantly less expensive when compared to the overhead that goes into facilitating structured support groups (Bateganya, Amanyeiwe, Roxo, & Dong, 2015). The financial stipulations of structured support groups must be considered, especially when health outcomes and attending such meetings are linked.

Those working directly with WLWH as either nurses, health care providers, social workers, or even case managers must continue to assess where these women are regarding disclosing their HIV status, specifically to sexual partners. When WLWH feel empowered enough to disclose their HIV status, there are multiple benefits for them. However, this benefits the sexual partner of WLWH, particularly if they are HIV-negative. Disclosing one's HIV status helps to decrease the number of new HIV infections. Decreasing new HIV infection rates is one of the many objectives of the National HIV/AIDS Strategy. If health care and social professionals notice that a woman

is struggling with disclosing her HIV status or has specific questions about the matter, it is important to know what resources are available to assist in her progress toward disclosing.

It is important to examine the power dynamics between WLWH and their significant others. Health care professionals or those working as advocates for WLWH should frequently inquire about violence in the relationships and who is making important decisions about matters such as sex and future reproductive plans. Being able to offer positive reinforcement when a woman can acknowledge that she makes such decisions will empower her to continue to be an active decision-making participant in her relationship.

Implications for Future Research

Although this study provides meaningful data to the science of nursing, there are areas of research that are still warranted. For the past 35 years, the health care community has been trying to understand the effects of HIV on the human body and individuals' personal lives. HIV is now a manageable chronic condition, and WLWH are beginning to regain control of their lives since their diagnoses. Times have changed and are changing, and the needs of WLWH are evolving, too. More qualitative research is needed in order to get a better understanding of what WLWH are now experiencing. Once these lived experiences are known, researchers can continue to expound on such data, implementing interventions, or other experimental designs to assist WLWH further.

Limitations

The findings of this study are limited to two urban areas in North Carolina. The lived experiences of women with HIV living in these cities may not be the experiences of those women with HIV living in more rural parts of North Carolina or other parts of the country. It is important to highlight that the majority of the participants in this study identified racially as African-American/Black, and two of the women identified as Caucasian/White. The responses gathered from this study could be unique to mostly African-American/Black women living in the south and not as transferable to Caucasian, Hispanic, or women of other ethnicities and WLWH in other regions in the United States. The experiences of WLWH who volunteered to participate in this study may not reflect the experiences of WLWH who did not volunteer to participate in this study. The women in this study were in heterosexual relationships. The findings from this study may not apply to women who are in same-sex relationships. A larger sample may provide additional insight.

Significance of the Research

Previously, qualitative studies have explored reproductive decision-making among HIV-positive women. These studies, however, explored the phenomenon in a very broad sense, outside of the United States, or focused primarily on health care provider communication (Finocchario-Kessler, Dariotis et al., 2010; Kirshenbaum, Hirky, Correale, & Goldstein, 2004; Matthews et al., 2013; Rogers et al., 2016). Although these studies have contributed to the science of nursing, there is still a noticeable gap in the

literature about the lived experience of HIV-positive women in the United States regarding intimate relationship power and reproductive decision-making.

Reproductive decision-making factors previously investigated using quantitative methods have studied the correlations among HIV-positive women in the presence of having a serodiscordant partner, the extent and quality of health care provider communication, the woman's desire to give birth, and the existence of a history of childhood and adult sexual abuse (Chen et al., 2001; Finger, Clum, Trent, & Ellen, 2012; Finocchario-Kessler, Dariotis, et al., 2010; Rahangdale et al., 2014; Rhodes et al., 2016). Although there has been extensive research to identify correlations between various factors and HIV-positive women's reproduction decision-making, there is still a need for more qualitative research examining the power dynamics between WLWH and their male significant other regarding reproductive decision-making. These gaps in the literature are what led to this phenomenological study examining the lived experiences of WLWH regarding intimate relationship power and reproductive decision-making.

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